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**FEARING FEAR ITSELF:
THE PROPOSED GENETIC INFORMATION
NONDISCRIMINATION ACT OF 2005 AND
PUBLIC FEARS ABOUT GENETIC
INFORMATION**

*Rivka Jungreis**

“Men and women will increasingly be judged not by the color of their skin but by the content of their chromosomes.”¹

INTRODUCTION

With the completion of the Human Genome Project in 2003, medicine and scientific research have embarked on a new era of possibility.² Among the prospects to which we can look forward as a result of this development are improved disease diagnosis and assessment of disease susceptibility, vastly improved

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¹ Andrew Sullivan, *The Way We Live Now: 7-23-00: Counter Culture; Promotion of the Fittest*, N.Y. TIMES, July 23, 2000, at F16 (proposing that in the wake of the Human Genome Project, genetic discrimination is both rational and inevitable).

² See *The Future of Genomics: Hearing Before the Subcomm. on Health of the H. Comm. on Energy and Commerce*, 108th Cong. (2003) (statement of Francis A. Collins, Director, National Human Genome Research Institute).

treatment and outcomes, and the progression of scientific research.³ Yet, along with the promise that genetic testing shows, new genetic technologies create additional possibilities for discrimination based on a person's genetic makeup.⁴ Pursuant to this concern, numerous propositions for federal legislative initiatives targeting genetic discrimination in health insurance and in the workplace have appeared in Congress over the last decade.⁵

This Note argues that a federal statute addressing genetic discrimination in the workplace and in insurance underwriting is prudent. Although the fear of genetic discrimination remains more persistent than the discrimination itself, it is important to address that fear, as it deters many people from undergoing genetic testing.⁶ This Note also argues that educational initiatives alone cannot accomplish a reduction of the fear in a timely manner.

Section I provides a brief overview of genetic information and the current state of genetic testing. Section II discusses the occurrence of genetic discrimination in employment and in health insurance, and Section III describes H.R. 1227, the Genetic Information Nondiscrimination Act of 2005 (GINA), which is the current version of proposed federal legislation targeting such discrimination.⁷ Section IV sets forth a comprehensive assessment of the desirability of passing such

³ *See id.*

⁴ *See* Genetic Discrimination in Health Insurance, What is the issue?, <http://www.genome.gov/10002328> (last visited Oct. 16, 2006).

⁵ Genetic Discrimination in Health Insurance, What are the legislative protections?, <http://www.genome.gov/10002328> (last visited Oct. 16, 2006) ("Nine bills were introduced in the 106th Congress (1999-2000), and four in the 107th Congress (2001-02)."). Five bills were introduced in the 108th Congress (2003-04). In the current Congress, a bill was unanimously passed in the Senate, and is pending in the House. *See* Federal Legislation about Genetic Privacy, <http://www.genome.gov/11510239> (last visited Oct. 16, 2005).

⁶ *See* Brian C. Watts, *V. Health Law: The Genetic Testing Privacy Act*, 2003 UTAH L. REV. 807, 809 (2003).

⁷ H.R. 1227, 109th Cong. (2005).

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legislation. The Note concludes that federal legislation is warranted, and that GINA provides a viable solution to the problems of genetic discrimination.

I. BACKGROUND ON GENETIC INFORMATION; CURRENT DEVELOPMENTS

Genetic information is contained in the DNA of every living organism.⁸ Each molecule of DNA, or deoxyribonucleic acid, is composed of two paired strands of nucleotides which are twisted together to form a double helical structure.⁹ Nucleotides contain one of four nitrogenous bases.¹⁰ Each nucleotide base pair is connected to the next, forming the chain of pairs that make up DNA.¹¹ In human cells, DNA is organized into twenty-three matched pairs of chromosomes.¹² The DNA codes for the production of specific proteins in the cell, thereby directing the cell's function.¹³ The vast majority of DNA found in human cells is uniform among all human beings.¹⁴ However, variations in the ordering of base pairs in an individual's DNA account for differences in the population.¹⁵ During replication of the cell's DNA, mistakes in the arrangement of the nucleotide bases can occur, resulting in mutations of the genetic material.¹⁶

The recently completed Human Genome Project¹⁷ has opened

⁸ *DNA*, Funk & Wagnalls New Encyclopedia (2005).

⁹ Nicholas Wade, *Watson and Crick, Both Aligned and Apart, Reinvented Biology*, N.Y. TIMES, Feb. 25, 2003, at F3.

¹⁰ *DNA*, *supra* note 8.

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ Jonathan Weems, *A Proposal for a Federal Genetic Privacy Act*, 24 J. LEGAL MED. 109, 111 (2003).

¹⁵ *Genetics*, Funk & Wagnalls New Encyclopedia (2005).

¹⁶ *Id.*

¹⁷ The Project was completed in 2003, and provides a blueprint of all of the genetic data contained in the human genome. All About the Human Genome Project, <http://www.genome.gov/10001772> (last visited Sep. 26, 2006).

up new avenues of discovery for scientists and physicians seeking to understand the underlying genetic bases of various diseases and pathological states.¹⁸ It is believed that almost every human illness has a genetic component.¹⁹ By comparing the known genetic sequence garnered from the Human Genome Project with the genetic sequence of an affected population, scientists can identify the segment of the genome that is implicated in a particular condition.²⁰ The capability for such identifications has led to the development of genetic testing. The detection of the presence or absence of particular DNA fragments in an individual's genome is invaluable for accurate diagnosis of disease and for determination of the propensity of a patient to develop various conditions.²¹ As scientists continue to unravel the genetic code, the significance of genetic testing will surely increase.²²

There are currently over 900 different genetic tests

¹⁸ See Stephanie L. Anderson, *Genetic Privacy: A Challenge to Medico-Legal Norms*, Graeme Laurie, 25 J. LEGAL MED. 119, 119 (2004) (book review).

¹⁹ Abigail L. Rose, Nikki Peters, Judy A. Shea & Katrina Armstrong, *Attitudes and Misconceptions about Predictive Genetic Testing for Cancer Risk*, 8 COMMUNITY GENETICS 145, 148 (2005). This notion may be what prompted James Watson, the co-discoverer of the structure of DNA, to declare, "In large measure, our fate is in our genes." Leon Jaroff, *The Gene Hunt Scientists*, TIME, March 20, 1989, at 67.

²⁰ Jennifer Chorpening, *Genetic Disability: A Modest Proposal To Modify the ADA to Protect Against Some Forms of Genetic Discrimination*, 82 N.C.L. REV. 1441, 1442 (2004).

²¹ See, e.g., Weems, *supra* note 14. An individual's DNA can be easily examined once a tissue sample is obtained. A variety of procedures have been developed to accomplish this. *Id.*; See also Jordan K. Garrison, Note, *Courts Face the Exciting and the Inevitable: DNA in Civil Trials*, 23 REV. LITIG. 435, 438 (2004) (quoting French Nobel laureate Jean Dausset on the value of genetic testing, "medicine was, in its history, first of all curative, then preventative and finally predictive, whereas today the order is reversed: initially predictive, then preventative and finally, only in desperation, curative.").

²² See, e.g., Weems, *supra* note 14; Anita Silvers & Michael Ashley Stein, *Human Rights and Genetic Discrimination: Protecting Genomics' Promise for Public Health*, 31 J. L. MED. & ETHICS 377, 377 (2003).

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available.²³ Some of these tests are diagnostic, while others identify susceptibility to specific diseases.²⁴ It is critical to understand the significance of these tests, and perhaps more importantly, to understand their limitations. A genetic test “can tell if a mutation is present, but that finding does not guarantee that disease will develop.”²⁵ For example, a genetic test revealing that a woman’s DNA contains the BRCA1 gene indicates that she has an 80% chance of developing breast cancer.²⁶ However, it is entirely possible that she will never develop the disease.²⁷ Equally important, a negative result of a BRCA1 test does not mean that a woman is risk-free.²⁸ She still sustains many other risk factors (both genetic and environmental).²⁹ Although the result of this particular genetic test does not conclusively predict whether a woman will or will not develop breast cancer, the test remains useful because it allows a high risk individual to take preventative steps to reduce the probability of occurrence of disease.³⁰

More controversial are tests which screen for diseases for which there are no known ways of avoiding or limiting the severity of the disease.³¹ In addition, most pathophysiological conditions are complex, many requiring an interaction between

²³ See Human Genome Project Information: Gene Testing, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml (last visited Oct. 28, 2005).

²⁴ *Id.*

²⁵ Lydia Schindler, Donna Kerrigan, Jeanne Kellen & Brian Hollen, National Cancer Institute, Understanding Gene Testing (2005), <http://nci.nih.gov/cancertopics/understandingcancer/genetesting/Slide29>.

²⁶ *Id.*

²⁷ *Id.*

²⁸ *Id.*

²⁹ Only five to ten percent of all breast cancer incidence is attributed to a genetic factor. See National Cancer Institute, Genetic Testing for BRCA1 and BRCA2: It’s Your Choice (2002), <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>.

³⁰ See, e.g., Mendel E. Singer & Randall D. Cebul, *BRCA1: To Test or Not to Test, That is the Question*, 7 HEALTH MATRIX 163, 164 (1997).

³¹ See Schindler et al., *supra* note 25, at <http://nci.nih.gov/cancertopics/understandingcancer/genetesting/Slide32>.

two or more defective genes.³² For many conditions, such as heart disease and diabetes, genetic susceptibility must be understood within the context of other important factors such as environmental influences, nutrition, and lifestyle.³³

II. OCCURRENCE OF GENETIC DISCRIMINATION

Along with enhanced understanding and treatment of human disease, the completion of the Human Genome Project along with the growing availability of genetic testing has resulted in increased concern about genetic discrimination.³⁴ Genetic discrimination has been defined in various ways. In one widely cited study of genetic discrimination, the term was defined as “the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests.”³⁵ Others extend the term to include “such denials on the basis of assumptions stemming from family histories . . . as well as from ethnic group identification.”³⁶

³² GRAEME LAURIE, *GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS* 94 (2002). Diseases which are caused by a single defective gene, such as cystic fibrosis, muscular dystrophy, and retinitis pigmentosa are more predictable. Jordan K. Garrison, Note, *Courts Face the Exciting and the Inevitable: DNA in Civil Trials*, 23 REV. LITIG. 435, 438-439 (2004).

³³ Jacquelyn Ann K. Kegley, *Confused Legal and Medical Policy: The Misconceptions of Genetic Screening*, 19 MED. & L. 197, 200 (2000). This explains the statement of Dr. Craig Venter at an event celebrating the completion of the Human Genome Project, “Our physiology is based on complex and seemingly infinite interactions amongst all our genes and the environment, just as our civilization is based on the interactions amongst all of us.” *Remarks by President Bill Clinton and British Prime Minister Tony Blair at Announcement on Human Genome Project*, Fed. News Serv. (2000).

³⁴ Following the announcement in 2000 that a rough map of the human genome had been created, this concern was expressed by Dr. Francis Collins, Dr. Craig Venter, and President Bill Clinton. *See Remarks by President Bill Clinton and British Prime Minister Tony Blair at Announcement on Human Genome Project*, Fed. News Serv. (2000).

³⁵ Lawrence O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J. L. & MED. 109 (1991).

³⁶ *See* Janet L. Dolgin, *Personhood, Discrimination, and the New*

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Concerns about the misuse of genetic information, whether the information is gleaned from a genetic test or from an individual's family history, are valid. While the discrimination may occur in a variety of arenas, the two particular areas of concern which have emerged are the employment setting and health insurance.³⁷

Genetic testing prior to finalizing employment decisions has become increasingly commonplace.³⁸ Information obtained in a genetic screen can be used to predict the likelihood of certain risks associated with the potential employee, such as the need for increased health care benefits and workers' compensation claims.³⁹ It might also be used to predict cost-related factors such as potential absenteeism or employee turnover.⁴⁰ Employers may request genetic information prior to hiring an employee in order to ascertain various safety risks linked to the nature of the employment.⁴¹ Several recent surveys indicated that workplace genetic discrimination does occur with some frequency.⁴²

Genetics, 66 BROOK. L. REV. 755, 771 (2001).

³⁷ Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, 29 AM. J. L. & MED. 77, 83 (2003). Other areas in which genetic discrimination may occur include child custody disputes, adoption prospects, and abortion. *Id.*

³⁸ Brian M. Holt, *Genetically Defective: The Judicial Interpretation of the Americans with Disabilities Act Fails to Protect Against Genetic Discrimination in the Workplace*, 35 J. MARSHALL L. REV. 457, 460 (2002); See Silvers & Stein, *supra* note 22, at n.23.

³⁹ Holt, *supra* note 38, at 460-61.

⁴⁰ See Jeremy A. Colby, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J. L. & MED. 443, 462 (1998).

⁴¹ Chorpening, *supra* note 20, at 1445. For example, a workplace chemical, such as benzene, has been shown to be more carcinogenic in individuals with a particular genetic susceptibility. Screening potential employees for this sensitivity could result in a safer work environment. See *id.* at n.32.

⁴² A 1996 survey conducted by the Genetic Alliance found 13% of respondents had experienced various forms of employment discrimination based on their genetic makeup. Watts, *supra* note 6, at 809. In 1989, a Congressional study found at least 12 Fortune 500 companies that used genetic monitoring to screen their employees. Robert F. Rich & Julian

Further, these issues have reached the courtroom as well via employees who claimed they were discriminated against on the basis of their genetic information.⁴³

In many instances, an employee's genetic predisposition to develop a disease will have no impact on job performance.⁴⁴ Indeed, in the employment setting, this information is typically not discovered until after an offer of employment has been extended, indicating that the employer has already made a factual determination that the applicant is qualified to perform the job.⁴⁵ Since genetic tests indicate only a propensity to develop a disease or condition, the employee may never be affected by it at all. Therefore, it is important to safeguard job applicants from genetic discrimination.

Similarly, insurance companies have a cost incentive to discriminate based on information obtained through genetic tests, as this information can be an indicator of probable risk.⁴⁶ Indeed, pricing of insurance has always reflected risk, and in this way, people who are at lower risk are able to avoid the cost

Ziegler, *Genetic Discrimination in Health Insurance—Comprehensive Legal Solutions for a (Not so) Special Problem?*, 2 IND. HEALTH L. REV. 5, 5 (2005). For a detailed discussion of the current state of genetic testing in the workplace environment, see Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 232-37 (2000).

⁴³ E.g. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998) (in which an employer required genetic testing of particular groups of individuals prior to employment); in another case, the E.E.O.C. brought suit against Burlington Northern Santa Fe Railroad for secretly testing its employees for a rare genetic condition. The case was settled for 2.2 million dollars. See National Human Genome Institute, *Cases of Genetic Discrimination* (2006), <http://www.genome.gov/12513976>.

⁴⁴ See Nancy Lee Jones & Alison M. Smith, *Genetic Information: Legal Issues Relating to Discrimination and Privacy*, CRS REP. FOR CONG. NO. RL30006, at 4-5 (2005).

⁴⁵ See Nicole Silvestri, *Echazabal and the Threat to Self-Defense: The Most Recent Call for a Consistent, Interstate Genetic Nondiscrimination Policy*, 7 U. PA. J. LAB. & EMP. L. 409, 421 (2005).

⁴⁶ David F. Partlett, *Misuse of Genetic Information: The Common Law and Professionals' Liability*, 42 WASHBURN L.J. 489, 503 (2003).

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of subsidizing the higher risk population.⁴⁷

The Genetic Alliance, a national advocacy group for individuals with genetic diseases, recently reported that it receives an average of two complaints per week about genetic discrimination.⁴⁸ However, the frequency of such complaints has not translated into frequent lawsuits by the victims. The discrepancy may be due not only to the fact that genetic discrimination can be difficult to prove, but also to the lack of a comprehensive genetic discrimination statute under which to sue. The current mélange of state and federal laws addressing genetic discrimination is, for the most part, too weak to support potential claims.⁴⁹ Some victims have indicated a hesitancy to sue over genetic discrimination for fear of bureaucratic barriers as well as further negative treatment resulting from publicity of their genetic data.⁵⁰

External pressures exist for both insurers and employers to avoid discriminating based on genetic factors.⁵¹ Some insurers may be cognizant of the limitations of genetic tests as predictors of disease, while others may want to avoid the possibility of potentially damaging discrimination lawsuits.⁵² Employers may also seek to avoid such suits.⁵³ However, occurrences of genetic discrimination in both employment and insurance are expected to increase over time as genetic testing becomes more comprehensive and methods even more sophisticated.⁵⁴

⁴⁷ *Id.* at 503-04.

⁴⁸ See Steve Lohr, *I.B.M. to Put Genetic Data of Workers Off Limits*, N.Y. TIMES, Oct. 10, 2005, at C1.

⁴⁹ See discussion of state and federal legislation *infra* Part IV.B-C; See also Tresa Baldas, *Legal Tension Grows over Genetic Tests; Privacy, Potential Discrimination are Major Concerns*, NAT'L L.J., Oct. 31, 2005, at P1.

⁵⁰ See Peter Aldhous, *Victims of Genetic Discrimination Speak Up*, NEW SCIENTIST, Nov. 5, 2005, at 7.

⁵¹ Partlett, *supra* note 46, at 518-19.

⁵² *Id.*

⁵³ *Id.* at 519.

⁵⁴ See Ronald M. Green & A. Matthew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J.L. & TECH. 571

Moreover, refinement of gene testing methodology will lead to reduced testing costs, further broadening the appeal of such tests to employers and insurers.⁵⁵

III. PURPOSE & SCOPE OF GINA—THE GENETIC INFORMATION NONDISCRIMINATION ACT

The Genetic Information Nondiscrimination Act⁵⁶ (GINA) was unanimously approved in the U.S. Senate on February 17, 2005.⁵⁷ An identical companion bill was introduced in the House of Representatives in March 2005.⁵⁸ In addition to prohibiting genetic discrimination by employers and insurers,⁵⁹ GINA contains provisions safeguarding the privacy of genetic information.⁶⁰ Despite the unanimous Senate approval as well as the support of President Bush⁶¹ and numerous interest groups such as the American Medical Association and the ACLU,⁶² the bill remains pending in the House.⁶³

GINA was introduced as a targeted effort to combat genetic

(1998); *See also* Rich & Ziegler, *supra* note 42, at 14.

⁵⁵ Rich & Ziegler, *supra* note 42, at 5.

⁵⁶ Genetic Information Nondiscrimination Act, S. 306, 109th Cong. (2005) (identical to H.R. 1227, 109th Cong.).

⁵⁷ *See* Bill Summary & Status for the 109th Congress, S. 306, <http://www.thomas.gov/cgi-bin/bdquery/z?d109:SN00306:@@@R> (last visited October 11, 2006).

⁵⁸ Genetic Information Nondiscrimination Act, H.R. 1227, 109th Cong. (2005).

⁵⁹ *See id.*

⁶⁰ *Id.*

⁶¹ Helen Dewar, *Senate Backs Safeguards for Genetic Data; Employers, Insurers Targeted*, THE WASH. POST, Oct. 15, 2003, at A10; *Statement of Administration Policy, S. 306 – Genetic Information Nondiscrimination Act of 2005*, reprinted in 151 CONG. REC. S. 1481 (daily ed. Feb. 16, 2005).

⁶² Rich & Ziegler, *supra* note 42, at 5.

⁶³ The legislation remains pending at the time of this publication. *See* Bill Summary & Status for the 109th Congress, H.R. 1227, <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:h.r.01227> (last visited September 8, 2006). There are currently 232 cosponsors in the House. *Id.*

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discrimination.⁶⁴ Its supporters found existing federal and state laws inadequate to provide the necessary protections to individuals seeking genetic tests.⁶⁵ GINA is designed to combat discrimination which is based solely on genetic information, that is, information obtained through a genetic test or indicated by the occurrence of a defect or disease in an individual's family.⁶⁶ Further, the existence of a request by an individual or an individual's family member for genetic testing is also protected genetic information.⁶⁷ The Act restricts both insurers and employers from using genetic information to discriminate in several ways.

Title I of GINA amends three existing federal laws in order to expressly prohibit insurers from restricting or denying enrollment in any health plan based on an individual's genetic information.⁶⁸ It also prevents insurers from setting an individual's premiums based on such information, or using such information for any underwriting purposes.⁶⁹ Insurers are also barred from requiring an individual to undergo a genetic test as a condition of insurability or of continuing coverage.⁷⁰ GINA provides broad protection to group health plan members by forbidding the adjustment of premiums for an entire group based on the genetic information of one or more individuals within the group.⁷¹

Under Title II, employers, employment agencies, and labor organizations may not make hiring or membership decisions or otherwise discriminate against an individual based on that

⁶⁴ See Genetic Information Nondiscrimination Act, H.R. 1227, 109th Cong. § 2 (2005).

⁶⁵ *Id.*; See also discussion *infra* Part IV.B-C.

⁶⁶ H.R. 1227, 109th Cong. § 201 (2005).

⁶⁷ *Id.*

⁶⁸ H.R. 1227, 109th Cong. §§ 101–103 (2005). The following federal laws are amended by GINA: The Employee Retirement Income Security Act of 1974, The Public Health Service Act, and Title XVIII of the Social Security Act. *Id.*

⁶⁹ H.R. 1227, 109th Cong. §§ 101(b), 104(b)(2) (2005).

⁷⁰ H.R. 1227, 109th Cong. § 101(b) (2005).

⁷¹ *Id.* at § 101(a)(2)-(3).

person's genetic information.⁷² For the most part, these entities may not "request, require, or purchase genetic information" about their employees, although there are five categories of exception.⁷³ If an employer obtains genetic information through an exception, the employer may only disclose the information to specific parties as mandated by the particular exception.⁷⁴ Finally, Title II provides remedies to various groups of employees who have been the victim of an employment practice contrary to the provisions of the Act.⁷⁵ The remedies include damages as well as costs and fees.⁷⁶

In accordance with the still evolving science of genetic testing and the uncertainties inherent in legislating a matter not yet fully developed, the drafters of GINA included a provision in the Act which provides for a review of the legislation six years after its enactment.⁷⁷ Specifically, the bill provides for the establishment of a Genetic Nondiscrimination Study Commission six years after GINA is passed, to study the impact of the legislation, to report on the current status of genetic science, and to make recommendations to Congress accordingly.⁷⁸

The Genetic Information Nondiscrimination Act of 2005 differs from previously proposed genetic nondiscrimination

⁷² *Id.* at §§ 202(a), 203(a), 204(a) (2005).

⁷³ *Id.* at §§ 202(b), 203(b), 204(b) (2005). The exceptions include, *inter alia*, where health or genetic services are offered by the employer as part of a wellness program, where the employee provides written authorization, where necessary for an employer to comply with the provisions of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613), and where the genetic information is to be used for monitoring of the effects of toxic substances in compliance with a Federal genetic monitoring regulation such as the Occupational Safety and Health Act of 1977 (30 U.S.C. 801). *Id.*

⁷⁴ H.R. 1227, 109th Cong. § 206(b) (2005). For example, if the information was collected in order for the employer to comply with the provisions of the Family and Medical Leave Act, the information may be disclosed in connection with the employer's compliance with the Act's requirements. *Id.*

⁷⁵ H.R. 1227, 109th Cong. § 207 (2005).

⁷⁶ *Id.*

⁷⁷ *Id.* at § 208(b).

⁷⁸ *Id.*

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legislation in several ways. Its definition of “genetic information” is more narrow, so that it excludes information about a genetic disease that is evident through a manifested disease or condition, as well as information obtained through a genetic test when the information is related to a manifested disease or condition.⁷⁹ Other distinctions include the requirement that individuals with discrimination claims seek redress with the Equal Employment Opportunity Commission (EEOC) before filing claims for damages in court, and the adoption of standards for the amount of punitive damage awards that can be obtained.⁸⁰ With these modifications, the current bill may be able to address some of the concerns that have prevented legislation from moving forward in previous sessions of Congress.

IV. WHY FEDERAL GENETIC NONDISCRIMINATION LEGISLATION
MUST BE PASSED

Although GINA has generally achieved widespread backing and acceptance,⁸¹ some key groups remain unconvinced of the need for federal genetic nondiscrimination legislation.⁸² The bill’s opponents, most notably the U.S. Chamber of Commerce, cite several basic reasons for their reluctance to support the bill. As a threshold matter, they do not find genetic discrimination different from other types of health status discrimination.⁸³

⁷⁹ *Id.* at § 201 (2005).

⁸⁰ H.R. 1227, 109th Cong. § 207 (2005).

⁸¹ See discussion *supra* Part III. In the House of Representatives, H.R. 1227 has 232 cosponsors. See Bill Summary & Status for the 109th Congress, H.R. 1227, <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:h.r.01227> (last visited September 8, 2006).

⁸² The two major groups opposing the legislation are the U.S. Chamber of Commerce and the National Association of Manufacturers. Frequently Asked Questions: Genetic Information Nondiscrimination Act (H.R. 1227), <http://geneticfairness.org/faq.html> (last visited November 25, 2005).

⁸³ See *Hearing Before the H. Subcomm. on Employer-Employee Relations of the H. Comm. on Education and the Workforce*, 108th Congress (2004) (statement of Lawrence Z. Lorber, Partner, Proskauer Rose LLP, on

Further, they maintain that recently enacted state genetic discrimination laws, as well as existing federal antidiscrimination laws, provide sufficient protections against genetic discrimination.⁸⁴ Some believe that genetic discrimination rarely occurs, and that non-legislative means can be employed to vanquish such fears.⁸⁵ This section addresses each of these claims and concludes that the need for a statute such as GINA is significant.

A. Genetic Discrimination is Different from Other Types of Discrimination

1. Genetic Information is Different than Ordinary Medical Information

Commentators caution against singling out parts of the population for inclusion in an antidiscrimination statute because of the likelihood that every person possesses genetic defects to some extent.⁸⁶ Arguably, it is difficult to differentiate between discrimination based on genetic information and discrimination based on other medical or circumstantial information, particularly for multifactorial diseases.⁸⁷ Genetic exceptionalism, the idea that a person who has a genetic predisposition to a disease should receive extra protection, but a person with an environmentally based disease should not, has been cited as an argument against legislation such as GINA.⁸⁸ One concern of those who warn against genetic exceptionalism is that legislating

behalf of the United States Chamber of Commerce).

⁸⁴ *See id.*

⁸⁵ *See id.*; Mark A. Hall & Stephen S. Rich, *Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counselors*, 28 J. L. MED. & ETHICS 245, 254-55 (2000).

⁸⁶ *See* Chorpening, *supra* note 20, at 1472; Susan M. Wolf, *Beyond Genetic Discrimination: Toward the Broader Harm of Geneticism*, 23 (4) J.L. MED. & ETHICS 345 (1995).

⁸⁷ *See* Silvers & Stein, *supra* note 22, at 382.

⁸⁸ *See* Chorpening, *supra* note 20, at 1472.

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against genetic discrimination, in and of itself may effectively label those who are discriminated against as inferior to the purportedly “normal” population.⁸⁹

Despite these arguments, genetic discrimination is separate and distinct from other sorts of discrimination. While it has been suggested that genetic information should not be singled out for protection beyond other health related information,⁹⁰ genetic information differs significantly. More than just another variety of medical examination, genetic testing “offer[s] tremendous quantitative differences.”⁹¹ Part of the difference is that genetic tests have the potential to reveal much more about a patient than any single medical test could. Testing for many genetic factors in a single profile is expected to become more cost effective, encouraging or even mandating testing for many factors even when information is only sought regarding one gene.⁹² A single genetic profile could include thousands of genetic risk factors for ailments ranging from diseases to psychosocial ailments, such as drug addiction or impulsiveness.⁹³ In this way, genetic testing carries long range prediction capabilities apart from those of more traditional medical tests.⁹⁴

Another distinguishing factor between genetic information and other medical information is the way in which such data might be used by insurers for underwriting purposes. Arguably, GINA’s restrictions on the use of genetic information adversely

⁸⁹ See Wolf, *supra* note 86. For a critique of Professor Wolf’s view of genetic exceptionalism, arguing that Wolf fails to explain why this sort of inequality is morally problematic, see Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, 29 AM. J. L. & MED. 77, 90-92 (2003).

⁹⁰ See, e.g., Chorpening, *supra* note 20, at 1441; Garrison, *supra* note 21, at 446 (discussing the finding of the Task Force on Genetic Information and Insurance of the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of the Human Genome Project, denying genetic exceptionalism).

⁹¹ Weems, *supra* note 14, at 111-12.

⁹² See Michele Schoonmaker & Erin D. Williams, *Genetic Testing: Scientific Background and Nondiscrimination Legislation*, CRS REP. FOR CONG. NO. RL32478, at 17 (2005).

⁹³ Weems, *supra* note 14, at 111.

⁹⁴ See Schoonmaker & Williams, *supra* note 92, at 16.

affect the underwriting process, resulting in poorly leveraged premiums among individuals with varying degrees of risk.⁹⁵ However, due to the inconclusive nature of most test results (given that the majority of genetic diseases are multifactorial), it is unclear that such calculations would be reasonable.

It is important to note that GINA does not address the use of medical information derived from methods other than genetic testing. Insurers may continue to use disease diagnosis (including diagnosis of a genetic disease) or other indicators of risk for underwriting purposes. The Act thus recognizes that it is the discriminatory use of inconclusive genetic information which requires protection, rather than a more appropriate use of existing disease for underwriting purposes. This is one of the ways in which H.R.1227 differs from previous incarnations of the bill, as its definition of "genetic information" excludes information obtained through a genetic test that is related to a clinically present disease.⁹⁶

2. *Widespread Fear of Genetic Discrimination Prevents People from Getting Tested*

Perhaps the largest distinction between genetic and other forms of discrimination lies in the public perception of genetic testing.⁹⁷ Despite the relatively low incidence of genetic discrimination, it is clear that many people forego possibly beneficial genetic testing for fear that discrimination may occur.⁹⁸ For similar reasons, many decline participation in potentially valuable research trials.⁹⁹ These fears exist in the absence of factual cases indicating that genetic discrimination

⁹⁵ Rich & Ziegler, *supra* note 42, at 40.

⁹⁶ See H.R. 1227, 109th Cong. § 201 (2005).

⁹⁷ See Anderson, *supra* note 18, at 124.

⁹⁸ Hall & Rich, *supra* note 85, at 245; See also Watts, *supra* note 6, at 809; Silvers & Stein, *supra* note 22, at 377.

⁹⁹ See Letter from The Secretary's Advisory Committee on Genetic Testing to Secretary Tommy Thompson 1 (2001), http://www4.od.nih.gov/oba/sacgt/ltr_to_secDHHS5-3-01.pdf.

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actually occurs to any significant extent.¹⁰⁰ Thus, even in the absence of the clear distinctions between genetic discrimination and other health-related discrimination described above, a practical need to address the fears arises.

It is imperative to understand the bases for this fear in any effort to combat their existence. For some, the fear may be explained by examining the historical perceptions of those who were thought to be genetically inferior.¹⁰¹ However, the majority of the fear may be attributed to scientific illiteracy in the general public,¹⁰² misconceptions among various groups of people,¹⁰³ and the existence of other sorts of privacy invasions which leave individuals apprehensive about how their genetic privacy will be protected.

There have been some historical incidents of discrimination on a genetic basis. In the early twentieth century the eugenics movement represented an attempt to weed out inferior people from the evolutionary chain.¹⁰⁴ The movement was spurred by Charles Darwin's work on evolution, and eugenics was thought to be the responsible way for society to promote the survival of the most suitable candidates to perpetuate the human species.¹⁰⁵ During the same time period, eugenics was also espoused by the Supreme Court, when it upheld a Virginia statute permitting the forced sterilization of a "feeble minded" woman, whose mother and child were also "feeble minded."¹⁰⁶ Writing for the

¹⁰⁰ Hall & Rich, *supra* note 85, at 245.

¹⁰¹ See, e.g., Rose et al., *supra* note 19, at 149.

¹⁰² See Cornelia Dean, *Scientific Savvy? In U.S., Not Much*, N.Y. TIMES, Aug. 30, 2005, at F3.

¹⁰³ Hall & Rich, *supra* note 85, at 245 (blaming misconceptions for reluctance to undergo genetic testing); See also Kegley, *supra* note 33, at 198 (discussing various misconceptions about genetic testing among individuals); Rose et al., *supra* note 19, at 148; Garrison, *supra* note 21, at 436 (indicating that even courts are not immune from misconceptions regarding genetic information).

¹⁰⁴ *Eugenics*, Funk & Wagnalls New Encyclopedia (2004).

¹⁰⁵ *Id.*

¹⁰⁶ *Buck v. Bell*, 274 U.S. 200, 205 (1927). Many states enacted sterilization laws targeting genetically defective populations, following early

majority, Justice Holmes determined that it was prudent to prevent the birth of children likely to drain the resources of society, reasoning that, "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."¹⁰⁷ The popularity of eugenics waned quickly during the Nazi era, when Hitler utilized eugenic philosophy to justify his schematic attempt to rid the world of allegedly inferior people, such as Jews and homosexuals.¹⁰⁸ Although eugenics as a discipline is not currently favored by the scientific community, and no longer appeals to the general public, some fear lingers concerning a revival of this sort of discriminatory practice.¹⁰⁹

A more recent instance of genetic discrimination occurred in the 1970s with the discovery of a gene associated with sickle cell anemia.¹¹⁰ The gene is found primarily in African-American populations.¹¹¹ Scientists found that carriers of the gene might be more susceptible to particular workplace toxins.¹¹² As a result, many African Americans reported experiencing discrimination in

developments in genetic science at the beginning of the twentieth century. The targeted defects included mental illness, blindness, and hearing loss, among others. GINA is an effort to prevent such discriminatory practices in the wake of the current major expansion of the capabilities of genetic science. *See* Genetic Information Nondiscrimination Act, H.R. 1227, 109th Cong. § 2 (2005).

¹⁰⁷ *Id.* at 207.

¹⁰⁸ *See* Weems, *supra* note 14, at 113.

¹⁰⁹ *Id.* *See also* Rose, *supra* note 19, at 148 (discussing a 2005 study in which some participants thought that the purpose of genetic testing was "to create a superior race"); Mark A. Rothstein, *Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation*, 71 *IND. L. J.* 877, 894 (1996) (discussing the possibility that genetic information may be used in the future for eugenic purposes).

¹¹⁰ *See, e.g.*, Marisa Anne Pagnattaro, *Genetic Discrimination and the Workplace: Employee's Right to Privacy v. Employer's Need to Know*, 39 *AM. BUS. L. J.* 139, 146-47 (2001).

¹¹¹ *Id.*

¹¹² *Id.*

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hiring and firing decisions.¹¹³ Some wrongly assumed that African Americans were more prone to genetic disease than other populations.¹¹⁴ It is possible that the fears underlying the reluctance of people to undergo genetic testing today may be understood in relation to this relatively recent occurrence of resultant discrimination.

In addition to these historical incidents of genetic discrimination, the fear of genetic discrimination among the general public may be attributed in part to scientific illiteracy. One genetic counselor at a cancer clinic explained that patients who come in to clinics are very much aware, and afraid of genetic discrimination.¹¹⁵ Yet for the most part, they “don’t know anything about genetics,” nor can they identify what a geneticist or a genetics counselor is.¹¹⁶ Jon Miller, who studies the current level of scientific understanding among Americans, found in a recent survey that less than one-third of adults in this country could articulate what DNA is.¹¹⁷ In a recent interview, Miller said that less than 25% of Americans “are scientifically savvy and alert,” while the remainder of the population “[doesn’t] have a clue.”¹¹⁸ Perhaps more worrisome is the alarm expressed by some that scientific literacy among biomedical policy leaders may be low as well.¹¹⁹

In a 1995 U.S. study, only about half of respondents

¹¹³ *Id.*

¹¹⁴ This incorrect assumption has been made regarding other groups, particularly Ashkenazi Jews. See Janet L. Dolgin, *Personhood, Discrimination, and the New Genetics*, 66 BROOK. L. REV. 755, 790 (2001). In fact, everyone shares a similar risk of genetic mutations, as indicated by the statement of Dr. Francis Collins, “There is no evidence that the burden of genetic flaws is greater for one population than another.” *Id.* at 791.

¹¹⁵ Hall & Rich, *supra* note 85, at 246.

¹¹⁶ *Id.*

¹¹⁷ Dean, *supra* note 102. Miller is the director of the Center for Biomedical Communications at Northwestern University Medical School, and is widely regarded as an authority on scientific literacy. *Id.*

¹¹⁸ *Id.*

¹¹⁹ JON D. MILLER & LINDA G. KIMMEL, BIOMEDICAL COMMUNICATIONS 302 (2001); See also Rich & Ziegler, *supra* note 42, at 8.

understood that if a doctor tells a couple that a genetic test indicates that they have a one-in-four chance of having a child with a genetic disease, each child that the couple has would sustain the same risk of having the disease.¹²⁰ Considering that about half of the populations in industrialized societies are active in deciding issues of public policy,¹²¹ and far less than half are considered “scientifically savvy,”¹²² it becomes clear that decision-making on many levels may be affected by fears that are not factually based.

Given that so many in the general population lack basic scientific understanding, it is not surprising that misconceptions about genetic testing abound. One common misconception is the belief that genes alone determine disease states.¹²³ With the exception of a few rare instances, most genes should actually be regarded as factors in a complex interaction of environmental elements which could potentially, but not determinedly, combine to bring about clinical disease.¹²⁴ In some cases, fear of genetic discrimination is tied to the belief that a defective gene is somehow indicative of a defective identity.¹²⁵ Under that perception, people are afraid that if a mutation or defect is discovered in their genetic makeup, they will be seen as inferior

¹²⁰ JON D. MILLER, RAFAEL PARDO, & FUJIO NIWA, PUBLIC PERCEPTIONS OF SCIENCE AND TECHNOLOGY 54(1997). Respondents were asked to choose between four possible interpretations of the meaning of “one-in-four chances.” The choices were:

- [a] if they have only three children, none will have the illness
- [b] if their first child has the illness, the next three will not
- [c] each of the couple’s children has the same risk of suffering from the illness
- [d] if their first three children are healthy, the fourth will have the illness.

Id. 54% of respondents selected choice c. *Id.*

¹²¹ *Id.* at 7.

¹²² Dean, *supra* note 102.

¹²³ See Rose et al., *supra* note 19, at 148.

¹²⁴ Kegley, *supra* note 33, at 200.

¹²⁵ *Id.* at 199.

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to others, and discrimination will result.¹²⁶ These sorts of pervasive misconceptions among the general population are often determinative of whether someone will choose a genetic test.¹²⁷ Indeed, even when patients are informed that there have not been widespread reports of genetic discrimination, many still choose to forego testing.¹²⁸

Misconceptions concerning genetic information occur among insurers as well. For example, some genetics counselors warn patients who are considering genetic tests about the possibility of resultant insurance discrimination because they believe that insurers are likely to misconstrue the results of tests.¹²⁹ An insurer may misinterpret a carrier as an affected person or a person at risk for the disease, or may not appreciate that although a genetic predisposition is present, symptoms may not manifest themselves for years.¹³⁰ Thus, it is thought that there is a lack of scientifically sound judgment on the insurer level as well.¹³¹ As a result, even when an individual understands the limits and capabilities of genetic testing, that individual may still resist testing for fear that other parties may misconstrue the meaning of the test results.

Another contributing factor to the fear of genetic discrimination is the vulnerability that people may feel as a result of other unrelated privacy intrusions. For example, identity theft is a common occurrence that receives widespread

¹²⁶ *Id.* The fears include fears of societal discrimination, fueled by general societal misunderstanding of genetic defects. See Ronald M. Green & A. Matthew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J.L. & TECH. 571, 584-85 (1998). This is particularly the case in the wake of recent claims by scientists of links between genetic mutations and behavioral traits. See Dolgin, *supra* note 36, at 767-68.

¹²⁷ Hall & Rich, *supra* note 85, at 245; see also Rose et al., *supra* note 19, at 145.

¹²⁸ Hall & Rich, *supra* note 85, at 245.

¹²⁹ *Id.* at 247.

¹³⁰ *Id.* For example, insurers “may not appreciate the fact that mild forms of muscular dystrophy exist in which symptoms do not occur for many years.” *Id.*

¹³¹ *Id.*; See also MILLER & KIMMEL, *supra* note 119, at 302.

media attention.¹³² This creates an increased awareness among people as to the potential effects of exposure of personal information to others. Widespread reports concerning the dissemination and abuse of confidential information have led many to blame the Internet and other technologies for an overall diminution of privacy interests.¹³³ The insecurity inherent in surrendering personal details such as social security numbers, addresses, and medical information, might carry over to genetic information as well.¹³⁴ In reality, as a result of the illiteracy and the misconceptions described above, individuals may be more fearful about loss of genetic privacy than any other closely held privacy interests.

In addition, the popular media repeatedly contains, with little basis, warnings about genetic discrimination.¹³⁵ This feeds into the public's general fears about invasions of privacy. Some have attributed public misconceptions about genetic testing to mass media reports which are often "misleading[,] and may confuse more than clarify."¹³⁶ Much of the information about genetic testing is learned outside the health care or research setting, including the learning done by health care professionals, insurers, and individual patients.¹³⁷

¹³² See, e.g., JOHNNY R. MAY, JOHNNY MAY'S GUIDE TO PREVENTING IDENTITY THEFT 1-2 (2004).

¹³³ See, e.g., Alison Gardy, *A Lost Baby, and the Pain of Endless Reminders in the Mail*, N.Y. TIMES Sep. 20, 2005, at F5 (describing a case of harassment by baby product companies following woman's failed pregnancy).

¹³⁴ See LAURIE, *supra* note 32, at 108.

¹³⁵ Hall & Rich, *supra* note 85, at 247; see also Neil A. Holtzman, Barbara A. Bernhardt, Eliza Mountcastle-Shah, Joann E. Rodgers, Ellen Tambor, & Gail Geller, *The Quality of Media Reports on Discoveries Related to Human Genetic Diseases*, 8 COMMUNITY GENETICS 133, 133-40 (2005) (Americans learn about genetic discoveries from television reports, which are often incomplete).

¹³⁶ Rose et al., *supra* note 19, at 149.

¹³⁷ See *id.*

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B. Individual State Laws Are Insufficient

There are currently thirty-three states with statutes specifically targeting genetic discrimination in employment. Additionally, every state except Mississippi, North Dakota, and Pennsylvania has statutes aimed at preventing genetic discrimination in health insurance.¹³⁸ However, the individual provisions in these statutes offer widely varying degrees of protection.¹³⁹ In particular, the threshold determination of what constitutes genetic information differs from state to state. While some states protect genetic information derived from individual or family medical histories as well as the results of genetic tests, others limit the protection to genetic test results alone.¹⁴⁰

Although state protection may seem sufficient on the surface, the portability of information, mobility of employees, and the existence of multi-state employers make individual state laws inadequate to address current needs.¹⁴¹ Due to variations in the protections offered by each state, multi-state employers face the burden of complying with a multitude of different state rules and regulations.¹⁴² Employees may face uncertainty when applying for jobs with such employers, or when considering a job opportunity in another state. An individual might also choose to forego genetic tests even if the individual lives and works in a state with a broad genetic discrimination statute because of the possibility that he may eventually move to another state in which his genetic information receives less protection. In order to effectively address the fears that are preventing people from pursuing genetic tests, as this note argues, uniform federal regulation is required.

Despite varying degrees of state protection, a large number

¹³⁸ National Conference of State Legislatures, Genetics Laws and Legislative Activity (2006), <http://www.ncsl.org/programs/health/genetics/charts.htm>.

¹³⁹ *Id.*

¹⁴⁰ *See id.*

¹⁴¹ Hall & Rich, *supra* note 85, at 253; *See also* Chorpening, *supra* note 20, at 1466.

¹⁴² *See* Silvestri, *supra* note 45, at 421.

of people remain unprotected under state laws because the federal Employee Retirement Income Security Act (ERISA) preempts state laws, thus preventing the protection of people in self-funded employer plans.¹⁴³ In short, state laws targeting genetic discrimination in health insurance only affect insurance plans outside of this major category. This exception to state protections may help explain why comparative reports on patient decisions to decline testing in states with or without genetic discrimination laws do not follow a pattern correlating to the existence of such laws.¹⁴⁴ This discrepancy apparent from the reports indicates that state initiatives have had little overall effect in combating patient fears.

C. Existing Federal Measures Are Insufficient

Contrary to what GINA opponents have suggested, existing pre-GINA federal legislation falls short of addressing all concerns at stake in genetic discrimination.¹⁴⁵ Examination of existing laws which might possibly address genetic discrimination indicates that these laws are not broad enough to cover all aspects of genetic discrimination and that they fail to allay the fears currently preventing individuals from undergoing genetic testing.¹⁴⁶ The existing federal provisions include The Americans with Disabilities Act, Title VII of the Civil Rights Act, The Health Insurance Portability and Accountability Act, and Executive Order 13,145.¹⁴⁷

¹⁴³ Employee Retirement Income Security Act of 1974, Pub. L. No. 93-406, 88 Stat. 829 (1974); *See* Hall & Rich, *supra* note 85, at 253. Nearly two-thirds of employers in the United States are self-insured. *See* Sherwin Chen, *Negotiating a Policy of Prudent Science and Proactive Law in the Brave New World of Genetic Information*, 53 HASTINGS L. J. 243, 259 (2001).

¹⁴⁴ Hall & Rich, *supra* note 85, at 253.

¹⁴⁵ Silvers & Stein, *supra* note 22, at 377-78.

¹⁴⁶ *See* Katharine A. Hathaway, *Federal Genetic Nondiscrimination Legislation: The New "Right" and the Race to Protect DNA at the Local, State, and Federal Level*, 52 CATH. U.L. REV. 133, 138-39 (2002).

¹⁴⁷ 42 U.S.C. § 12112 (2006) (Americans with Disabilities Act); 42

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1. The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) prohibits certain employers from requesting medical information from potential employees prior to extending an offer of employment.¹⁴⁸ Once an offer is extended, the employer may request that the potential employee submit to a medical examination or that he provide further information.¹⁴⁹ Such requests must be uniformly made of all job applicants.¹⁵⁰ Further, the exams or inquiries must be job-related and consistent with business necessity.¹⁵¹ Once these conditions are met, the employer may refuse to hire a disabled employee if reasonable accommodations cannot be made, or if the presence of the disability is a “direct threat” to others.¹⁵²

In order for an employee to receive protection from discrimination under the ADA, the employee must have a disability as defined by the Act.¹⁵³ It is unlikely that a genetic defect, particularly for an individual who has the defect but is currently asymptomatic, qualifies as a covered disability.¹⁵⁴

U.S.C. § 2000e-2(a) (2005) (Title VII of the Civil Rights Act); 29 U.S.C. § 1182(a)(F) (2005) (Health Insurance Portability and Accountability Act); Exec. Order No. 13,145, 65 Fed. Reg. 6877 (2000).

¹⁴⁸ 42 U.S.C. § 12112(d)(2)(A) (2006). The Act applies only to employers with fifteen or more employees. An employer with less than that amount is not covered. *Id.* at (5)(A).

¹⁴⁹ *Id.* at (d)(3).

¹⁵⁰ *Id.* at (d)(3)(A).

¹⁵¹ *Id.* at (d)(4)(A).

¹⁵² 42 U.S.C. § 12113(b) (2006). The Act defines “direct threat” as a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation. 42 U.S.C. § 12111 (3) (2006).

¹⁵³ 42 U.S.C. § 12112(a) (2006). The ADA defines “disability” as, “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.” 42 U.S.C. § 12102(2) (2006). It is unlikely that a genetic predisposition constitutes such a disability. *See Holt, supra* note 38, at 469-71.

¹⁵⁴ Holt, *supra* note 38, at 469-71 (discussing impairments that substantially limit major life activities, and judicial interpretations of “disability” under the ADA).

Additionally, individuals who are found to be carriers of a recessive gene would not receive protection under the Act.¹⁵⁵ The EEOC declared in a statement that discrimination based on genetic testing is covered under the ADA's third definition of disability ("being regarded as" having an impairment).¹⁵⁶ While courts may choose to view the EEOC statement as persuasive when faced with an individual genetic discrimination claim, they are by no means bound by it.¹⁵⁷ Indeed, as demonstrated by *Sutton v. United Airlines*, in which the Supreme Court clearly rejected an EEOC statement regarding another ADA provision, the EEOC's interpretation is not always dispositive.¹⁵⁸ In addition, under the "regarded as" definition of disability, courts have held that the employer must actually be mistaken as to the disability's existence.¹⁵⁹ Often, an employer may refuse a job applicant employment in order to avoid the risk that the potential

¹⁵⁵ A recessive gene is one that can only be expressed when the individual has inherited a copy of the recessive gene from both of the individual's parents. In a carrier of a recessive gene, only one copy of the gene is present, and therefore the gene will not be expressed. Such an individual is not only presently asymptomatic, but also does not sustain any predisposition for future disability caused by the gene. See Schoonmaker & Williams, *supra* note 91, at 4 and n.18. Yet under current federal laws, this person does not receive any assurances of protection from discrimination. See Pagnattaro, *supra* note 110, at 165.

¹⁵⁶ EEOC Compliance Manual, Definition of the Term Disability, § 902.8(a) (1995).

¹⁵⁷ Holt, *supra* note 38, at 465.

¹⁵⁸ *Sutton v. United Air Lines*, 527 U.S. 471, 482 (1999). The Supreme Court disagreed with the EEOC interpretation of disability to include correctable disabilities such as vision impairment. *Id.*

¹⁵⁹ *EEOC v. Rockwell Int'l Corp.*, 60 F. Supp. 2d 791 (N.D. Ill. 1999), *aff'd*, 243 F.3d 1012 (7th Cir. 2001) (holding that an employer may reject applicants who have a propensity to future disability, as long as the employer is not regarding the applicants as currently disabled); *Sutton v. United Air Lines*, 527 U.S. 471, 484-85 (1999) (holding that rejection of applicants seeking positions as airline pilots because they required corrective lenses for vision impairments was not barred by the ADA. The employer knew that the applicants' vision with corrective lenses in place was not impaired, thus it did not regard the applicants as currently disabled).

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employee may develop an impairment in the future.¹⁶⁰ Thus the employer has not regarded the applicant as having any current impairment.¹⁶¹ Accordingly, an individual with a genetic predisposition to illness who is as yet asymptomatic, may be barred from bringing suit under the ADA if the employer refuses to hire the individual in order to avoid a future risk.¹⁶²

The statutory language of the ADA has contributed to a relatively narrow interpretation of “disability,” as it cites the Congressional finding that there are around 43 million Americans with disabilities.¹⁶³ An expansion of ADA protected disabilities to include genetic defects would implicate virtually every living person,¹⁶⁴ undermining the legislative intent to provide specific protection to the 43 million people currently classified as disabled.¹⁶⁵ Such an inclusion would serve as a validation of common misperceptions about genetic information.¹⁶⁶ It would lead to the incorrect assumption that genetic predisposition to disease is in fact an impairment.¹⁶⁷ Clearly, this would discourage people from undergoing testing.

Although the Supreme Court has not directly addressed the issue, the Court has hinted that it will not allow the inclusion of genetic predispositions in the ADA’s definition of disability.¹⁶⁸

¹⁶⁰ See Chorpening, *supra* note 20, at 1453-54; Silvers & Stein, *supra* note 22, at 379.

¹⁶¹ Chorpening, *supra* note 20, at 1454; *see also* EEOC v. Rockwell, 60 F. Supp. 2d 791 (N.D. Ill. 1999), *aff’d*, 243 F.3d 1012 (7th Cir. 2001).

¹⁶² See Chorpening, *supra* note 20, at 1454.

¹⁶³ 42 U.S.C. § 12101(a)(1) (2006).

¹⁶⁴ *Hearings on Genetic Information in the Workplace: Hearing Before the Senate Comm. on Health, Educ., Labor and Pensions*, 106th Cong. (2000) (testimony of Francis S. Collins, M.D., Ph.D., Director of National Human Genome Research Institute), *available at* <http://www.genome.gov/10001380>.

¹⁶⁵ Chorpening, *supra* note 20, at 1458.

¹⁶⁶ See discussion of common misperceptions *supra*, Part IV.A(2).

¹⁶⁷ Holt, *supra* note 38, at 482.

¹⁶⁸ See *Bragdon v. Abbot*, 524 U.S. 624, 661 (1998) (Rehnquist, C.J., concurring in part and dissenting in part) (comparing an individual with presymptomatic HIV to an individual with a genetic marker for a debilitating disease, in that neither impairment substantially limits a major life activity, as

For example, in *Chevron U.S.A., Inc. v. Echazabal*, the Supreme Court allowed an extension of the “direct threat to others” defense to cover threats to oneself as well as to others.¹⁶⁹ The Court upheld the denial of employment to an individual with a medical condition that might become worse in the particular work environment.¹⁷⁰ Under this expanded definition of “direct threat,” employers are given a broader defense to ADA claims that could allow genetic factors to be considered in hiring decisions.¹⁷¹

Other judicial opinions have demonstrated that the scope of the ADA does not extend to genetic discrimination. In *EEOC v. Rockwell*, a Seventh Circuit case, an employer used predictive medical tests to screen potential employees for an indicator that they may develop a particular disability in the future.¹⁷² The applicants were not disabled at the time of the test, nor was there any guarantee that they would become disabled in the

required for inclusion in the ADA); *Sutton v. United Air Lines*, 527 U.S. 471, 487 (1999) (holding that correctable myopia may not be considered a disability under the ADA because such inclusion would encompass too many people). Both of these opinions cautioned against an over-inclusive definition of disability under the ADA which could then extend the scope far beyond the intention of Congress.

¹⁶⁹ *Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73, 78-79 (2002).

¹⁷⁰ *Id.* The case involved an individual who was denied employment at an oil refinery when a post-offer physical exam revealed that he had a liver condition which could be exacerbated over time. *Id.* In a post-Echazabal 8th Circuit case, an insulin-dependent diabetic was denied employment at a single-pharmacist pharmacy which did not provide for uninterrupted meal breaks. The court noted that the employer could validly assert a “direct threat to self” argument. *Orr v. Wal-Mart Stores, Inc.* 297 F.3d 720 (8th Cir. 2002).

¹⁷¹ See, e.g., *Silvers & Stein, supra* note 22, at 380. GINA does not contain a “direct threat” defense, thus broadening the scope of the prohibited discrimination. See H.R. 1227, 109th Cong. (2005).

¹⁷² *EEOC v. Rockwell*, 60 F. Supp. 2d 791 (N.D. Ill. 1999), *aff'd*, 243 F.3d 1012 (7th Cir. 2001). Job applicants at the Rockwell International Corporation were required to undergo nerve conduction tests to detect the presence of neuropathy, a condition which indicates susceptibility of an individual to the development of nerve disorders such as carpal tunnel syndrome. *Id.* at 1014.

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future.¹⁷³ Yet the employer rejected applicants who had a propensity to develop the disability.¹⁷⁴ The court found that the employer did not violate the ADA because the individuals were not currently disabled, and the employer did not mistakenly regard them as disabled.¹⁷⁵ This decision points toward the conclusion that genetic discrimination by employers will not be barred by the ADA, as most employers use genetic information in a predictive manner, rather than as an indicator of a current disability.¹⁷⁶

2. Title VII of the Civil Rights Act

Title VII of the Civil Rights Act is also an inadequate means of addressing genetic discrimination because while it prohibits an employer from basing an employment decision on race, color, religion, sex, or national origin,¹⁷⁷ genetic discrimination does not readily fit into any of these categories. Although a small percentage of genetic diseases closely correlate with race, sex, or national origin, no disease is exclusively linked to these factors.¹⁷⁸

Title VII yields a cause of action for genetic discrimination only to the extent that an employer chooses to single out job applicants belonging to a particular Title VII category for a genetic test. For example, in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, an employer subjected its black and female employees to genetic testing for sickle cell trait, syphilis, and pregnancy.¹⁷⁹ The court found that the employees' claims under Title VII were valid, as the discriminatory acts of the employer specifically targeted members of the Title VII categories of race

¹⁷³ *Id.*

¹⁷⁴ *Id.*

¹⁷⁵ *Id.* at 1018.

¹⁷⁶ See Holt, *supra* note 38, at 468.

¹⁷⁷ 42 U.S.C. § 2000e-2(a) (2005).

¹⁷⁸ Chorpening, *supra* note 20, at 1463.

¹⁷⁹ *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1265 (9th Cir. 1998).

and sex.¹⁸⁰ Although the genetic discrimination in *Norman-Bloodsaw* violated Title VII, much of the fear about genetic discrimination arises in situations in which employers discriminate purely on the basis of a genetic factor that predisposes an individual to illness. Such discrimination does not correlate to any category of individuals protected under the existing Title VII.¹⁸¹

This discrepancy has led some to suggest modification of Title VII's categories to include genetic predispositions.¹⁸² However, doing so would prevent employers from considering the potential impact of the genetic predisposition on workplace safety, including threats to other employees or the general public.¹⁸³ Genetic information is unlike race, sex, religion, and national origin in that it at times raises valid concerns over public safety and welfare.¹⁸⁴ Yet under Title VII, exceptions such as threat to others or business necessity are not permitted.¹⁸⁵

3. *The Health Insurance Portability and Accountability Act*

The earliest Congressional attempt to specifically address genetic discrimination was included in the Health Insurance Portability and Accountability Act (HIPAA) of 1996.¹⁸⁶ Although the legislation contains a specific provision prohibiting health insurers from denying coverage based on genetic data about an individual, it does not prevent the insurer from

¹⁸⁰ *Id.* at 1271-72.

¹⁸¹ Chorpening, *supra* note 20, at 1463.

¹⁸² Holt, *supra* note 38, at 481-82.

¹⁸³ Chorpening, *supra* note 20, at 1464.

¹⁸⁴ *Id.* For example, an airplane pilot with a genetic predisposition that is highly predictive of a propensity for epileptic seizures at high altitudes may be a valid safety concern for the airline; *But see* Holt, *supra* note 38, at 482 (arguing that a Title VII modification is appropriate because genetic discrimination is another form of "inappropriate prejudices").

¹⁸⁵ *See* Chorpening, *supra* note 20, at 1464.

¹⁸⁶ Health Insurance Portability and Accountability Act, 29 U.S.C. § 1182(a)(F) (2005).

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increasing premiums for groups based on genetic data.¹⁸⁷ The provisions of HIPAA apply only to group health insurers, and not to privately held plans.¹⁸⁸ Further, the statute does not define “genetic information,” leaving open the possibility that information obtained from family medical histories may not be protected.¹⁸⁹ Genetic discrimination in workplace employment decisions is not addressed by HIPAA.¹⁹⁰ The narrow focus of this legislation does little to persuade people to undergo genetic testing.¹⁹¹

4. Executive Order 13,145

In an acknowledgment of the need for regulation of the use of genetic information by employers, President Clinton issued Executive Order 13,145 in February 2000.¹⁹² While this Order addresses some of the concerns about genetic discrimination, it applies only in the context of federal employers.¹⁹³ The Order can do little to alleviate concerns about discrimination, as it does not address insurers, and it has no effect on non-federal employers.¹⁹⁴ In addition, the Order provides an exception for employers who use genetic information “exclusively to assess whether further medical evaluation is needed to diagnose a current disease, condition, or disorder.”¹⁹⁵ Because the Order contains no further elucidation of the terms “disease, condition, or disorder,” employers may be able to retain significant

¹⁸⁷ 29 U.S.C. § 1182(b)(2) (2005).

¹⁸⁸ *Id.* at (a)(1) (2005).

¹⁸⁹ *See Dolgin, supra* note 36, at 783.

¹⁹⁰ Chorpening, *supra* note 20, at 1467.

¹⁹¹ Hall & Rich, *supra* note 85, at 249; *See also* Green & Thomas, *supra* note 54, at 571 (finding that HIPAA is not a sufficient means of addressing genetic discrimination).

¹⁹² Exec. Order No. 13,145, 65 Fed. Reg. 6877 (2000).

¹⁹³ *Id.* The Order includes provisions barring federal employers from using protected genetic information in hiring, firing, and employee compensation decisions. *Id.*

¹⁹⁴ *Id.*

¹⁹⁵ *Id.*

flexibility in their use of genetic information.¹⁹⁶

D. Other (Non-Legislative) Methods of Circumventing the Fears are Inadequate

Because it is the fear of genetic discrimination, rather than genetic discrimination itself, that is at the root of this problem, the use of legislation to combat it must be carefully weighed. Policy makers need to be aware of the complexities of influencing a behavioral change in people, and the law should not be treated “as a simple ‘tool’ for influencing . . . complex behaviors.”¹⁹⁷ Legislating on the basis of existing fears, rather than existing unwanted activity, presents unique challenges such as an increased opportunity for unintended consequences and an increased possibility of unnecessary regulation.¹⁹⁸ In addition, it has been suggested that rather than using legislation to eliminate all of the risk, educational initiatives should be undertaken with a focus on “increasing more accurate perception of the risk.”¹⁹⁹

Increased public education about the nature of genetic information could effectively alleviate fears and misconceptions.²⁰⁰ Arguably, implementation of educational

¹⁹⁶ See Jennifer Krumm, *Why Congress Must Ban Genetic Discrimination in the Workplace*, 23 J. LEGAL MED. 491, 516 (2002). “[M]any different personality traits and characteristics could fit within these exceptions.” *Id.*

¹⁹⁷ Scott Burris, *Driving the Epidemic Underground: A New Look at Law and the Social Risk of HIV Testing*, 12 AIDS & PUBLIC POLICY J. 66, 72 (1997).

¹⁹⁸ Letter from Genetic Information Nondiscrimination in Employment Coalition, U.S. Chamber of Commerce, *Re: S.1053, the Genetic Information Nondiscrimination Act of 2003*, (June 12, 2003), available at <http://www.uschamber.com/NR/rdonlyres/epm4okq4dony6fqjgkwnmjf7tu6h2ktiop3jv4xuqfx6ryx7351xaj77y5tpyloq3uceb7hlmaafacrlc5blcallasa/2003GINECoalitionSenateLetter603FINAL.pdf#search=%22Genetic%20Information%20Nondiscrimination%20in%20Employment%20Coalition%22>.

¹⁹⁹ Hall & Rich, *supra* note 85, at 255.

²⁰⁰ *Id.* at 254-55. This is also the view of The U.S. Chamber of Commerce, a major opponent of GINA. See *Genetic Non-Discrimination: Examining the Implications for Workers and Employers: Hearing Before the H. Subcomm. on Employer-Employee Relations of the H. Comm. on*

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initiatives such as government-sponsored public courses on basic genetics and improvement of cross-disciplinary communication between scientists, policy makers, and ethicists, can succeed in raising public awareness to some extent.²⁰¹ Furthermore, some commentators predict that in the future, genetic information will become such a fundamental part of our lives that people will inevitably learn how to understand and interpret the information in an appropriate way.²⁰²

However, the current state of scientific understanding in the general population is extremely low.²⁰³ Genetic science has quickly become a major medical and scientific force, requiring that policy decisions be made rapidly, leaving little time to carry out major educational campaigns.²⁰⁴ The most practical solution to address the current needs of patients may be legislation, or at the very least, a combination of legislative and educational initiatives, because the time required to effect a change of public sentiment is daunting.²⁰⁵ The mere possibility that public understanding of genetic science will improve in the future does not preclude the necessity for immediate action to address the current state of affairs. Further, GINA provides for the establishment of a committee to evaluate the status of the implemented legislation after a period of time, at which point any change in public acceptance of or attitudes toward genetic testing can be accounted for.²⁰⁶

Education and the Workforce, 108th Congress (2004) (statement of Lawrence Z. Lorber, Partner, Proskauer Rose, LLP, on behalf of the U.S. Chamber of Commerce).

²⁰¹ See Chen, *supra* note 143, at 257.

²⁰² John C. Fletcher and Dorothy Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome is Mapped*, 39 EMORY L. J. 747, 757-58 (1990).

²⁰³ See discussion, *supra* Part IV.A(2).

²⁰⁴ MILLER & KIMMEL, *supra* note 119, at 237.

²⁰⁵ Hall & Rich, *supra* note 85, at 255; See also Rose et al., *supra* note 19, at 150.

²⁰⁶ H.R. 1227, § 208(b) (2005).

E. The Significance of Genetic Testing for Public Healthcare and Scientific Research

Because of the significance of genetic testing in two spheres—that of the advancement of scientific research,²⁰⁷ and that of the individual's pursuit of optimal healthcare²⁰⁸—efforts must be made to address public fears and promote wider public acceptance of these tests. Indeed, the unique importance of the tests may be considered yet another distinguishing factor between genetic discrimination and discrimination based on other health-related information.²⁰⁹ The unique challenges of using legislation to target an existing fear are balanced by the unique importance of genetic testing.²¹⁰ Whether or not the fear of genetic discrimination is justified, the fact remains that it is preventing people from receiving the wide range of benefits of recent scientific progress.²¹¹ This concern speaks to the urgency of the need for comprehensive federal legislation.²¹²

The individual who undergoes genetic testing may glean important information leading to better prevention and treatment options. For example, individuals with genetic mutations that indicate a high susceptibility to colorectal cancer can follow recommended guidelines such as undergoing a routine colonoscopy beginning at age 25.²¹³ A woman who learns that she is at a high risk for developing breast cancer due to mutations in her BRCA1 or BRCA2 genes may increase her screenings or take other preventative measures.²¹⁴ Other

²⁰⁷ Rose et al., *supra* note 19, at 145.

²⁰⁸ See R. Verhoeff, Physicians' Perception of Genomic Medicine, 8 COMMUNITY GENETICS 184, 184 (2005).

²⁰⁹ See Hellman, *supra* note 37, at 93.

²¹⁰ The challenges are described *supra*, Part IV.D.

²¹¹ See, e.g., Silvers & Stein, *supra* note 22, at 377.

²¹² See Gina Kolata, *Using Gene Tests to Customize Medical Treatment*, N.Y. TIMES, Dec. 20, 1999, at A1 (quoting Dr. Francis Collins, director of The National Human Genome Research Institute).

²¹³ Rose et al., *supra* note 19, at 145.

²¹⁴ *Id.* Other preventative measures may include taking Tamoxifen for 5

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important applications of genetic test results for healthcare include characterization of leukemias in order to tailor treatment options accordingly, and new tests available to determine the efficiency of specific drugs when used in conjunction with specific genetic profiles.²¹⁵

In situations in which the need for genetic testing is crucial, it is unlikely that fear of genetic discrimination will prevent people from pursuing it.²¹⁶ Those who are already exhibiting signs of a disease are not likely to be deterred from undergoing a test to confirm a diagnosis.²¹⁷ In that instance, their insurability will not significantly change because the carrier will, at any rate, establish that he has the disease from clinical reports.²¹⁸ Additionally, most prenatal genetic testing is not affected by patient fears of genetic discrimination.²¹⁹ This is attributable to the nature of such tests, as they target spontaneous mutations (which have no implication for other family members), and a result indicating a severe genetic abnormality usually leads to termination of the pregnancy.²²⁰

In other situations, the deterrent fears may not have any serious implications for patients. For example, for those who have a significant family history of a disease, testing is often not critical because those individuals are already aware that they are at a high risk and are likely taking preventative measures. For this group, test results indicating a high propensity for the disease will change nothing, and the patient, anticipating future illness, will likely conclude that the test is not worth the risk of losing their insurance.²²¹ Additionally, some available genetic

years or bilateral mastectomy. *Id.*

²¹⁵ At least two new drug treatments, Herceptin for breast cancer and Azathioprine for inflammatory bowel disease, are designed for use only in populations with a particular genetic factor. *See* Schoonmaker & Williams, *supra* note 92, at n.29.

²¹⁶ Hall & Rich, *supra* note 85, at 250.

²¹⁷ *Id.*

²¹⁸ *Id.*

²¹⁹ *Id.* at 247.

²²⁰ *Id.*

²²¹ Hall & Rich, *supra* note 85, at 250-51.

tests are thought to be entirely unnecessary.²²² These include tests for diseases that cannot be prevented, and for which knowledge of one's genetic risk will not have any practical significance.²²³

The opportunities yielded by the Human Genome Project for the improvement of public health will remain limited by scientific investigation into the impact of particular genetic sequences on human conditions. Accordingly, the National Human Genome Research Institute has created the Genomes to Life initiative, which is committed to scientific research into the clinical significance of the data acquired by the Human Genome Project.²²⁴ However, in order to accomplish this, scientists depend on the willingness of individuals to undergo genetic testing for research purposes. This willingness has been compromised by fears of resultant discrimination in employment or health insurance.²²⁵

Comprehensive federal legislation must be in place in order to allay the concerns of people contemplating undergoing testing, whether for purposes of scientific research studies or personal health, because of the critical importance of genetic testing in these two spheres.²²⁶ A common law evolutionary model, which allows the common law to evolve over time to deal with developments not contemplated by existing laws,²²⁷

²²² See generally Uses of Genetic Testing (2004), <http://www.genetests.org/servlet/access?id=8888891&key=Mq8YIMK4mMjyU&fcn=y&fw=GLTS&filename=/concepts/primer/primerusesof.html>.

²²³ Hall & Rich, *supra* note 85, at 250.

²²⁴ U.S. Dept. of Energy Office of Science, Genomics: GTL (2006), <http://genomicsgtl.energy.gov/>.

²²⁵ See Rose et al., *supra* note 19, at 150.

²²⁶ Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania recently told the New York Times, "If you want a genomic revolution, then you better have policies, practices and safeguards that give people comfort and trust." Steve Lohr, *IBM to Put Genetic Data of Workers Off Limits*, N.Y. TIMES, Oct. 10, 2005, at C1.

²²⁷ Partlett, *supra* note 46, at 508. (discussing the possibility of allowing the common law to evolve over time through judicial interpretations of existing law, rather than instituting new legislation to address genetic discrimination).

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will not suffice in this case. While it is possible that existing laws might ultimately grow to address some of the concerns about genetic discrimination, time constraints make this option unworkable. The passage of time will significantly delay much needed scientific progress as well as serve to deprive patients of critical information that could be obtained from genetic testing.

CONCLUSION

The Genetic Information Nondiscrimination Act, as described above, currently awaits attention in the House of Representatives.²²⁸ Genetic nondiscrimination legislation is sorely needed, as existing measures do not sufficiently address the complexities of genetic discrimination. Although the necessity for legislation has most likely been fueled by general misunderstanding and/or ignorance of the underlying scientific bases for genetic testing, the current state of affairs results in vulnerable populations failing to benefit from potentially life-saving or life-altering medical advances. Therefore, in the absence of non-legislative solutions, Congressional legislative power, as this note argues, must address the issue.

²²⁸ See Bill Summary & Status for the 109th Congress, H.R. 1227, <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:h.r.01227> (last visited September 8, 2006).