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NOTES

Genetic Discrimination in Health Insurance

I. INTRODUCTION

Why should we allow someone to benefit from their genetic endowment to the detriment of those less fortunate than themselves? Persons with detrimentally aberrant genomes should not be subject to medical insurance discrimination made possible by genetic research funded by the public. Such research is conducted for the purpose of advancing science and human well being, not the perfection of insurance underwriting. Why should we sacrifice the potential medically beneficial fruits of society's investments in genetic research so that private insurance companies, which were profitable before humanity had the means to genetically predict an individual's medical future, might offer the lowest possible insurance rates to a handful of genetically "superior" individuals?

In the late 1980's, biology and technology had advanced to the point where genetic *maps* could be calculated.¹ With maps of the human genome, scientists could begin to decipher which genes, when altered, resulted in specific diseases present in the human population. Scientists realized that if the source and process of genetic diseases could be discerned, appropriate therapies for the afflicted might be developed, freeing afflicted individual, from the consequences of their conditions, and allowing them to return as productive, healthy members of society.

Recognizing the potential benefits of a complete map of the human genome, an international team of more than one hundred scientists in government, university and commercial laboratories have labored collectively in an effort termed the Human Genome Project.² To accomplish its share of the work needed, in 1989 the United States established the National Center for Human Genome Research (NCHGR) under the National Institutes of Health, which was renamed the National Human Genome Research Institute in 1997.³ The NCHGR funded research facilities throughout the country and established the Division of Intramural Research to apply genetic findings toward diagnosis and treatment of genetic diseases and acquired genetic disorders.⁴

So far, disorders and diseases which can be predicted or identified with genetic tests have been relatively rare.⁵ The advent of tests for some genetic forms of breast

1. Genetic linkage maps give the position of genes on a chromosome. The location of each individual gene is referred to as a loci. The distance between loci determine the likelihood or possibility of two different genes being inherited together (referred to as linked genes) or separately following cross-over of the inherited chromosomes of each parent.

2. *National Human Genome Research Institute* (visited Jan. 4, 1998) <<http://www.aamc.org/research/adhocgr/ncgr.htm>>.

3. *Id.*

4. *Id.*

5. See Sheryl Stolberg, *Insurance Falls Prey To Genetic Bias; The DNA Revolution is a Blessing*

and colon cancer, combined with the continued development of other genetic tests by the Human Genome Project, however, means that genetic information's use, or misuse, will affect greater numbers of individuals as genetic knowledge expands.

Debates have raged over who should have use of information gleaned from our genes by genetic research which will impact our potential medical fates. Should the inescapable, and now soon to be unconcealable, content of our genes be a private matter confined to the realm of a doctor-patient relationship, or should such information be publicly accessible to entities like health insurers for use in medical underwriting?

Access to the results of genetic testing would provide insurance companies with the information required to form three new categories of individuals in their underwriting schemes. One category would consist of asymptomatic individuals who stand a substantial probability of acquiring adult-onset disabilities from conditions like Huntington's disease, myotonic dystrophy, and amyotrophic lateral sclerosis.⁶ A second category would also consist of asymptomatic individuals, but they would merely be predisposed, not certain, to develop diseases like heart disease, diabetes, some cancers, and mental disorders.⁷ The third new category of potential insurees would consist of those who would never themselves become ill, but who are carriers of genes that could affect the health of any children they might have.⁸

The answer to who will pay what for whom in the area of health care must address how each of these categories of individuals' interests weigh against the interests of insurers and the rest of society. The question of who will pay has been addressed under state and federal law, as well as in political and ethical theory. To date, however, no legislation seems to have satisfactorily balanced the interests of individuals, economics and ethics.

and a Curse. It Tells Some the Potential for Disease, but Allows Companies to Deny Coverage. Some Fear This Is Only the Beginning of a Huge Dilemma., L.A. TIMES HOME EDITION, Mar. 27, 1994, at A1: Column 1; Metro Desk (stating that the following genetic disorders and diseases can currently be genetically tested for: 1. Amyotrophic lateral sclerosis (Lou Gehrig's disease)-a degenerative disease of the nervous system, 2. Delta-thalassemia which is prevalent in the Mediterranean, the Middle East and Southeast Asia-causes a breakup of the red blood cells, leading to anemia, spleen enlargement and sometimes abnormal growth of bones (fatal in early childhood if left untreated), 3. Charcot Marie-Tooth disease-causes abnormalities in the feet and hands, 4. Cystic Fibrosis-the most common lethal genetic defect, causing chronic lung infections and an inability to absorb fats and other nutrients, 5. Duchenne Muscular Dystrophy-the major form of muscular dystrophy in children. It causes progressive degeneration of the muscle fibers, 6. Fragile X Syndrome-a chromosomal disorder causing mental impairment, ranging from subtle learning disabilities to severe retardation and autism. Symptoms are generally more pronounced in boys, 7. Gaucher's disease-a disorder common to Ashkenazi Jews. The most severe form appears in infancy, causing central nervous system impairment and death within the first year, 8. Huntington's disease-a degenerative brain disorder, 9. Marfan Syndrome-a disease of the connective tissue that often strikes athletes, 10. Myotonic Dystrophy-Most common form of muscular dystrophy in adults. 11. Retinoblastoma-an inherited form of eye tumors in children. 12. Tay-Sachs disease-a brain disorder common among Ashkenazi Jews which results in death during early childhood).

6. Adrienne Asch, *Genetics and Employment, More Disability Discrimination*, in THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE 158, 161 (Thomas H. Murray et al. eds., 1996).

7. *Id.*

8. *Id.* Genetic disorders such as hemophilia, Duchenne muscular dystrophy, sickle cell anemia, cystic fibrosis and Tay Sachs require the inheritance of the defective gene from both parents. Receipt of only one deleterious copy of the gene makes one a "carrier" of the condition, unaffected by the condition but capable of passing the disease on to offspring if one's mate is also a carrier who also passes on the deleterious gene. *Id.*

This Note focuses on the justice of allowing genetic discrimination by medical insurers. It will provide a brief overview of some philosophical frameworks from which the issue of genetic discrimination can be studied before it explains why such discrimination should not be allowed. Legislative attempts to protect individuals from genetic discrimination in past acts and present bills will then be reviewed to demonstrate their inadequacies. Finally, it will conclude with some suggestions of legislation which would provide more meaningful protection against genetic discrimination than recent acts and bills have afforded.

II. PHILOSOPHICAL FRAMEWORKS

It has been generally held that only two ethical theories provide plausible means to systematically arrive at a moral judgement in any given circumstance.⁹ These two theories are Utilitarianism and Rawls' Theory of Justice.

Utilitarianism is an eighteenth century tradition best represented by the writings of two English philosophers, Jeremy Bentham and John Stuart Mill.¹⁰ The classical form of Utilitarianism is a doctrine of hedonism, where action is deemed to be ethical if it tends to promote greater happiness in society than any alternative actions will.¹¹ Newer forms of the doctrine include economically based Preference Utilitarianism which regards anything of economic value as a rational goal one can ethically seek, and Negative Utilitarianism which regards behavior that avoids disutility as ethical.¹²

The main argument against the use of any form of Utilitarianism as an ethical doctrine is its compatibility with a practice of sacrificing individuals so long as more members of society would benefit from such an act than suffer.¹³ As Mill himself admitted, the inability to provide desirable results with regard to cherished concepts like justice was Utilitarianism's greatest failure.¹⁴

In 1971, John Rawls' *Theory of Justice* was enthusiastically welcomed as an ethical theory that was just as plausible, systematic, and universally applicable as Utilitarianism, and yet adequately accounted for values such as justice.¹⁵ Rather than the hedonistic goal of the greatest happiness for the greatest number, Rawls asserted that ethical decisions within a society ought to be based upon principles its individual members would have agreed upon if they did not know what their particular position in society would be.¹⁶ Rawls referred to this state as behind a *veil of ignorance*.

From behind the veil of ignorance, Rawls claimed individuals would not seek to maximize utility, but instead would seek to provide safeguards against too severe of an existence. He predicted that they would provide for the maximum amount of personal liberty that could coexist with a distribution of wealth which would make the least well-off members of society as well-off as possible.¹⁷

9. *Ethics*, 18 ENCYCLOPEDIA BRITANNICA 515 (15th ed. 1994).

10. See generally *Philosophical Schools and Doctrines-Western-Utilitarianism*, 12 ENCYCLOPEDIA BRITANNICA 219 (15th ed. 1994).

11. This classical form is referred to as Ideal Utilitarianism.

12. See *supra* note 10.

13. See *supra* note 9.

14. See *supra* note 10.

15. See *supra* note 9.

16. See JOHN RAWLS, *A THEORY OF JUSTICE* 136-142 (1971).

17. This principle is Rawls' maximin principle in that the welfare of the worst-off members of society would be maximized. See *supra* note 9.

However, Rawls did not believe that his theory advocated socialism. This is evident in "that if we accept certain assumptions about the effect of incentives and the benefits that may flow to all from the productive labours of the most talented members of society, the maximin principle could allow considerable inequality."¹⁸

Rawls' Theory of Justice, rather than variants of Utilitarianism, is the more appropriate philosophical framework from which to consider the ethical nature of allowing health insurance discrimination through the use of genetic information in our society. Since the 1935 passage of the Social Security Act and the advent of the welfare state,¹⁹ our society has not had a utilitarian orientation. Rather, our society claims to seek liberty and justice for all, goals which can only be supported with Rawls' theories.

III. WHY GENETIC DISCRIMINATION SHOULD NOT BE ALLOWED

Prior to the advent of predictive genetic capabilities, created in part by the efforts of the Human Genome Project and other genetic research, the manner in which medical insurers handled treatments for genetic diseases mirrored the veil of ignorance envisioned in Rawls' Theory of Justice. No one had any means of ensuring that they, or their offspring, would not fall victim to one of the conditions or diseases we now know are the result of deleterious genetic mutations. Medical care for these conditions was not exempted from coverage by insurance policies at that time; nor, absent knowledge as to one's risks of falling victim to such a disease, was it likely that people would clamor for such exemption. Following the advent of predictive genetic technology, armed with the ability to know that they will not be struck with genetic based disease X, some individuals seek to avoid paying the price of insuring those, who technology can now discern will or might suffer the ravages of genetic diseases.²⁰

Indeed, "some insurers argue that it is actuarially unfair, and therefore morally unfair, to those at low medical risk when insurers do not exclude those at high risk from insurance pools."²¹ With Rawls' veil of ignorance lifted, many individuals, like the health insurance companies, claim that they should be allowed to benefit from the good fortune of their genetic endowment, much as an individual is allowed to benefit from being smarter than another, more athletic than another, etc.

But, what frequently goes unrecognized by proponents of such arguments is that society already limits the use of some forms of advantage with which those individuals are born. For example, society does not recognize any legitimate advantages or disad-

18. *Id.*

19. The welfare state includes such innovations as aid to physically and mentally handicapped individuals, unemployment benefits, and minimum-wage laws, all of which are based on principles of justice, not utilitarianism.

20. Insurance rates are set by a process referred to as underwriting. Underwriting is the actuarial process of determining what expenses a given pool of potential insureds will incur in medical expenses over the life of their policy and setting a sufficiently high rate for medical insurance coverage to ensure sufficient funds to cover expenses and still allow for a profit by the insurance company. If one were able to guarantee that a given population would not be subject to conditions which are expensive to treat medically, that group could safely be offered lower rates than the identical population absent such guarantees. Some genetically fit individuals claim that they should be allowed to form insurance pools which exclude genetically defective individuals so that they might reap the personal benefits of lowered insurance rates.

21. Norman Daniels, *The Human Genome Project and the Distribution of Scarce Medical Resources*, in *THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE* 173, 179 (Thomas H. Murray, et al. eds., 1996).

vantages in the distribution of opportunities and rights on the basis of sex or race despite the market advantages and disadvantages people frequently infer to them.

Why should we allow some to benefit from their genetic endowment any more than we permit them to benefit from having been born black or white, male or female? All of these traits are obtained simply by the luck of the draw, require no cultivation to develop and maintain, and merit no special recognition or privileges. Intelligence or sports ability, which benefit their possessors, require some degree of effort or cultivation on the part of the individual gifted with them. Genetics, race, and sex do not merit the recognition we allow intelligence, sports ability, and other talents in determining the legitimate assets an individual may use in furthering their interests. "Even among those philosophers who want to treat talents and skills as individual assets, only the strictest libertarians treat health status differences merely as 'unfortunate' variations and believe that there is no social obligation to correct for the relative advantages and disadvantages caused by disease or disability."²²

Clearly it is unethical for health insurers to discriminate based upon the genetic status of its clients. Various governmental entities have also come to this conclusion as well.

IV. WHY WE NEED LEGISLATIVE TREATMENT OF GENETICS-BASED MEDICAL INSURANCE DISCRIMINATION

In 1993, Dr. Paul Billings²³ had already found ninety-three cases of so-called genetic health insurance discrimination, even though scientists had only identified two percent of the human genome by this time.²⁴ By 1994, horror stories had seeped into popular news sources such as the *L.A. Times* story about an entire New Hampshire family who lost their health insurance because their eight-year-old was diagnosed with the genetic disorder called Fragile X Syndrome,²⁵ despite the fact that the remaining members of the family were unaffected by the disease. In desperation, the family contacted the "state's assistant insurance commissioner, a disability rights lawyer and a U.S. [S]enator . . . all of whom said it was the insurers' right" to cancel their coverage.²⁶ This family did not need anyone to tell them that genetic information can adversely affect not only the afflicted individual, but can also be used to prevent unaffected parents, siblings, cousins, and future offspring from acquiring reasonable health insurance.

The potential for genetic discrimination by health insurance companies was recognized as early as May 10, 1993, by the NCHGR. The NCHGR suggested a need for health insurers to place a "[m]oratorium on the use of genetic tests in underwriting until a program of universal basic health services is in place."²⁷ The NCHGR believed at that time that a combination of self-regulation and federal legislation would resolve

22. *Id.* at 183.

23. Dr. Billings is a clinical geneticist in Palo Alto, California.

24. Interview by Greg Lefevre with the child of a Huntington's Patient, on *Your Money* [CNN television broadcast, Jan. 23, 1993] (Jan. 23, 1993).

25. Fragile X Syndrome is a genetic disorder which impairs an individual's mental development, but is not considered a genetic disease. Rather it is referred to as a developmental disorder.

26. Stolberg, *supra* note 5, at 1.

27. *Health Insurers Should Impose "Moratorium" on Use of Genetic Tests in Underwriting — Task Force*, BLUE SHEET (F-D-C Reports, Inc., Washington, D.C.), May 12, 1993, available in LEXIS, Health Library, MEDJNL File.

unethical discrimination in the health insurance industry resulting from advances in genetic knowledge through the Human Genome Project. Unfortunately, it was evident by stories like that carried in the *L.A. Times* that self-regulation by the insurance industry was already insufficient to protect insurees from discrimination in 1994.

This lack of protection for genetically defective individuals remained an unresolved problem in 1997. During this span of time, state and federal legislatures have attempted to introduce legislation which would prevent discrimination against the genetically flawed by insurance companies, but to date none of the enacted legislation seems to have successfully ended genetic discrimination.

V. STATE LEGISLATION ENACTED TO PREVENT GENETIC DISCRIMINATION

By 1994, Ohio and Wisconsin already had, and California and New York were drafting, laws to prohibit insurers from using genetic information to deny individuals health insurance coverage.²⁸ The Wisconsin law,²⁹ for example, prohibited insurers from: (a) requiring or requesting an individual or family member to obtain a genetic test; (b) requiring or requesting directly or indirectly into the results of a genetic test; (c) conditioning the provision of insurance coverage or benefits on genetic testing; or (d) considering genetic testing in the determination of rates or any other aspect of insurance coverage or health care benefits provided to an individual whether an individual or a member of the individual's family has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual's family, were.³⁰

Wisconsin's legislation failed to state how these regulations would be policed, or how the enforcement would be funded. Enacted state laws "focus[ed] narrowly on genetic tests, rather than more broadly on genetic information generated by family history, physical examination or the medical record."³¹ Although state laws can and do prohibit using "the results of a chemical test of DNA or the protein product of a gene," insurers "may still use other physical/physiological (phenotype) indicators, patterns of inheritance of genetic characteristics, or even a request for genetic testing as the basis for discrimination."³² These problems, however, cannot be solved merely by expansively defining genetic information in state legislation due to the federal Employee Retirement Income Security Act (ERISA) laws.

While concerning an employee with AIDS, not a genetic disease, *McGann v. H & H Music Co.*³³ demonstrated "how state based prohibitions on genetic underwriting will be undermined."³⁴ After McGann had made his first claims under his employer's

28. Stolberg, *supra* note 5, at 1.

29. WIS. STAT. § 631.89 (1995).

30. WIS. STAT. § 631.89(2)(a)-(d) (1995).

31. *Prepared Testimony of Karen H. Rothenberg J.D., M.P.A., Marjorie Cook Professor of Law, Director Law & Health Care Program University of Maryland School of Law, Before the Senate Comm. on Labor and Human Resources, 104th Cong. (1996).*

32. *Id.*

33. *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991) (giving ERISA employers the right to change their self-insured benefit plans through ERISA).

34. Deborah A. Stone, *The Implications of the Human Genome Project for Access to Health Insurance*, in *THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE* 133, 149 (Thomas H. Murray et al. eds., 1996).

health insurance plan, the employer switched its commercial insurer to a self-insured plan.³⁵ The employer then capped coverage under this new plan for AIDS treatment at five thousand dollars, but allowed a one million dollar maximum for all other claims for medical care. The Fifth Circuit Court of Appeals declared that it was an:

employer's right to change its self-insured benefit plan in response to diseases or expenses incurred by a single employee. [footnote omitted] Of course, an employer might do the same thing for any other disease. No doubt it would be harder for an employer to cap benefits for relatively common diseases that afflict many employees and dependents, such as cancer or heart disease. But, like AIDS, genetic diseases tend to be less common and thus easier and more likely targets for employers looking for ways to cut the costs of their fringe benefits.³⁶

Thus, according to *McGann*, "[u]nder the Employee Retirement Income Security Act (ERISA), employers who self-insure are exempt from state insurance regulations (both statutory and regulatory)."³⁷ Since a "large proportion of the population receives health benefits from self-funded plans not subject to state insurance laws,"³⁸ protections against discrimination based on state legislation are unenforceable to constitute a solution to problems with genetic discrimination due to ERISA. Insurers, in concert with employers, in an attempt to limit their expenses in either premiums or disbursements, could and, no doubt would, in order to remain competitive, use ERISA to step around any state legislation regulating insurance use of genetic information.

VI. CONGRESSIONAL ACTS USED TO LIMIT GENETIC DISCRIMINATION

The Americans with Disabilities Act of 1990³⁹ (ADA) was not enacted with the specific intent of preventing health insurance discrimination. It was created in part to prevent a phenomenon referred to as *job-lock*,⁴⁰ which resulted in the onset of medically expensive disabilities. The ability to diagnosis latent genetic diseases resulted in a source of job-lock, which while not considered upon the ADA's enactment, created a need to expand the breadth of antidiscriminatory protection, which the ADA provided to employees. Some proponents of the ADA believed that this legislation would relieve workers from being locked to their jobs because of dependence upon a health insurance policy without which they could not financially survive when they or a dependent became disabled. Unfortunately, this legislation was not far-reaching enough to provide the relief its proponents sought.

The first problem with using ADA to combat genetic discrimination in obtaining employment with sufficient health insurance is that it does not apply to all employers. Beginning in July 1992, public and private sector employers of twenty-five or more employees were forbidden to discriminate based upon disabilities of potential employ-

35. Companies which self-insure their health care policies are those that only bear the cost of any claims incurred as a result of an employee's or dependent's medical expenses.

36. Stone, *supra* note 34, at 148.

37. *Id.* at 152.

38. Rothenberg, *supra* note 31.

39. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 (1995).

40. Job-lock is the position an employee faces when the employee's medical benefits, especially related to preexisting conditions coverage, does not transfer to a subsequent employer's benefit plan. Consequently, the employee is discouraged from seeking new employment for fear of losing these medical benefits and is locked into her current job.

ees.⁴¹ On July 26, 1995, these restrictions extended to all employers with fifteen or more employees. However, vast numbers of individuals working for small employers are exempted from coverage by the ADA's protections.

Furthermore, complaints under the ADA against limitations of fringe benefits like health insurance, are also similar to those of state legislation combating health insurance discrimination when suits were brought against companies using self-insured plans. As was seen in *McGann*, ERISA would once again be used to protect an employer's right to limit coverage based on inordinate medical expenses incurred by a few individuals who would endanger the fiscal solvency of the company, if they were to be included in that company's self-funded insurance plan.

The ADA is too simplistic in its scope to sufficiently protect people from health insurance discrimination by health insurers. Since the ADA addresses only employer/employee relations, it seemed to only address prevention of disability discrimination by employers. It did not seem to stop insurance companies from using the infamous preexisting condition clauses in health insurance policies. Sufferers of genetic defects or workers whose dependents have genetic defects are still locked to the jobs they had when they, or their dependents were first diagnosed with a costly or potentially financially devastating disease or disability.

Attempts were made to reform the ADA regulations of insurance companies, but these attempts have been minimally effective. "Some people have argued that the insurance company is a public entity and thus should be covered under the full provisions" of the ADA, "[b]ut there is other language in the ADA that says that insurance practices which conform to state principles—and most of the state principles talk about actuarial fairness—would be exempted on that basis."⁴²

At first glance this backdoor out of the ADA's regulatory powers over insurance companies might appear to be poor drafting, but it was actually a necessary evil. The logic behind such a provision in the ADA is that "if there's an actuarial basis for [insurance discrimination], it's okay. All insurance is discrimination of one sort or another. The question is, is it legal or not?"⁴³ Thus, if the discrimination falls within actuarial fairness as defined under state law, it is not actionable under the ADA, whether ethical or not.

VII. CONGRESSIONAL BILLS INTENDED TO END GENETIC DISCRIMINATION

The ADA's failure to prevent genetic discrimination as a result of ERISA's protections and the ADA's own actuarial fairness clause has led to the introduction of many bills in Congress. Some of the most recent congressional bills aimed at ceasing genetic discrimination by health insurers included: the Genetic Information Health Insurance Nondiscrimination Act of 1997⁴⁴ (GIHINA) sponsored by Representative Gerald B. Solomon (R-NY), the Genetic Privacy and Nondiscrimination Act of 1997⁴⁵ (GPNA) sponsored by Representative Clifford B. Stearns (R-FL), the Genetic Informa-

41. ERIC RANDALL, *NYPER ADA UPDATE, ADA-THE FIRST FIVE YEARS* (Mar. 1995).

42. Reginald Rhein, *Federal Disability Law Bans Genetic Discrimination*, BIOTECHNOLOGY NEWSWATCH, May 1, 1995, at 1.

43. *Id.*

44. H.R. 328, 105th Cong. (1997).

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

tion Nondiscrimination in Health Insurance Act of 1997⁴⁶ (GINHIA) sponsored by Senator Olympia J. Snowe (R-ME), and the Genetic Confidentiality and Nondiscrimination Act of 1997⁴⁷ (GCNA) sponsored by Senator Pete V. Domenici (R-NM). Each of these bills insightfully recognized elements that will need to be enacted into law if an end to genetic discrimination in the health insurance industry is to be obtained.

The greatest insight of the GIHINA was recognizing the need to forbid health insurance discrimination based upon requested *or received* genetic information or genetic test results. This provision is key toward stopping genetic discrimination in health insurance, because most information used by insurance companies in their medical underwriting is not surreptitiously obtained in violation of a person's privacy. Rather, it is gained through the answering of questions posed, and the release of medical records by the potential insuree to the insurance company in the insurance application, along with permission to obtain the potential insuree's record from the Medical Information Bureau (MIB).

The MIB "is an insurance industry-run data bank, accessible to nearly 800 member companies in the United States and Canada."⁴⁸ The member insurance companies input any relevant data they obtain from an individual, and all members have access to the information. As a result, when they seek health insurance, consumers find themselves facing an omniscient entity that knows, at minimum, all medical procedures and tests ever performed on them and paid for by a health insurer.

Complete cooperation on the part of the applicants in releasing their MIB records, and answering the applications' medical history questions, is induced by the inclusion of full disclosure guarantee clauses which render the insurance, if granted, invalid in the event that the applicants were not fully forthcoming in disclosures on their applications.

The release of medical records will often reveal what the applicants either do not consciously know or will not acknowledge about their genetic endowment. The release often includes such diverse sources as "physicians, other medical practitioners, hospitals, clinics, other medical facilities, insurance companies, and sometimes employers. . . [and at times any] organization, institution, or person that has any records or knowledge"⁴⁹ of the applicants' health.

Privacy is not technically violated by this process because the applicants sign away their rights. Arguments that privacy legislation could at least guarantee the rights of applicants to be informed as to how this information could potentially be used against them would be an empty right, given that there would be few or no other options than the release of medical records and medical histories if one desired to obtain health insurance. No competitive private market exists within the insurance industry because what the potential consumer actually faces is a "monopolist seller in the sense that insurers can choose their customers, and virtually all insurers have access to the same information about a potential customer,"⁵⁰ thanks to the MIB.

Laws limiting an insurer's ability to perform genetic tests, or obtain results of tests which were performed on those seeking health insurance, are irrelevant to the

46. S. 89, 105th Cong. (1997).

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

48. Stone, *supra* note 34, at 143.

49. *Id.* at 141.

50. *Id.* at 143.

accessibility of health coverage because these companies “do and will have virtually unlimited access to the information from genetic tests performed in the medical sphere.”⁵¹ Provisions in the GIHINA,⁵² forbidding discrimination based upon the request or receipt of genetic information or test results, are therefore necessary if further progress is to be made in combating genetic discrimination in health insurance.

The greatest contribution of the GPNA was its forward-looking provision directing the National Bioethics Advisory Commission to report to Congress its recommendations on providing protection for collecting, storing, and using genetic samples and data.⁵³ Provision like these will help ensure that future research on the Human Genome Project will not be precluded or unduly burdened by congressional efforts to prevent injuries from the data we have already extrapolated from our genes.

The GINHIA reminds us that it is not enough to merely regulate the insurance industry to end genetic discrimination. Regulation is usually only effective if it is coupled with sufficient punishment to induce compliance by the regulated industry. This Act suggests providing for compensatory, consequential, and punitive damages for violations of suggested amendments to ERISA, the Public Health Service Act, Title XVIII of the Social Security Act, or the Internal Revenue Code, in order to eradicate genetic discrimination by the health insurance industry.⁵⁴

The GCNA not only seeks to protect against unconsented disclosure of genetic information, but also regulates redisclosure of information which may have originally been legitimately received.⁵⁵ Such provisions should help to prevent the continued existence of the MIB which places the consumer of health insurance at a disadvantage when dealing with a health insurance company.

VIII. CONCLUSION

Genetic disease is not the fault of the individuals who suffer under its ailment. Prior to the identification of strange disorders and ailments which are being the result of genetic defect, many victims might have found coverage for their medical treatment from their ordinary health care coverage through an insurance company or their employer.

As our medical knowledge grew, thanks in part to government-funded research on genetics, additional legislation to protect individuals from high-rate discrimination, or the inability to gain medical insurance at all, was needed due to our newfound knowledge regarding the origins of such ailments. As we acquired more knowledge regarding inheritable traits, the list of individuals who needed protection also grew because the insurance industry actively avoided liability in covering afflicted individuals. While it may be natural for insurance companies to avoid covering individuals with genetic disease, they cannot ethically be allowed to shirk from such serious health policy issues.

The ADA is inadequate in its protection of people with genetic diseases and disorders, because by definition the insurance industry must use some degree of discrimination if they are to be allowed to use the underwriting techniques on which they

51. *Id.* at 134-35.

52. H.R. 328, 105th Cong. (1997).

53. H.R. 341, 105th Cong. § 7 (1997).

54. S. 89, 105th Cong. (1997).

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

were originally founded as a means of risk management for their consumers. The reason that some might find such an argument distasteful is that many individuals in our society today do not deem health insurance to be a means of risk management, but rather a means of obtaining the bodily integrity to make the most of their lives and participate equally within society. The ADA serves many purposes successfully, but protecting the genetically defective from an inability to gain health insurance is not one of them.

Privacy laws in theory would be a good idea as well to protect society from genetic discrimination by health insurers. People should be informed that insurance companies are not like a collection of individual agents competitively seeking business as a highly organized institution seeking collective protection of their respective competitive edges. But privacy laws are insufficient protection as well, since mere rights can easily be contracted away when one is not as powerful or worldly as the entity with which one contracts.

If we are to end genetic discrimination without foreclosing future progress in genetic research, we must enact a bill which encompasses at least all of the solutions outlined in the four bills cited. This new bill includes forbidding the use of any genetic information, or information from which genetic conclusions could be formulated, from being used in medical underwriting, regardless of its being obtained upon request or mere innocent receipt. We also must provide for punishments within such a bill to induce compliance with its provisions. We will have to ensure at the same time, however, that future genetic research will not be precluded or unduly restricted by the protections we grant individuals' genetic endowments. Finally, we must find a means to prevent the dissemination of genetic information received legitimately by one entity to others who were not originally authorized to receive such data. Only then will we have solved the vexing phenomenon of genetic discrimination.

*Lynn E. Egan**

* B.A., Political Science, Northwestern University, 1996; J.D., Candidate, Notre Dame Law School, 1999. This Note is dedicated to my mother, Carol, and in loving memory of my father, James.

