

Genetic Discrimination

Edited by Leanna J. Albertson

Authors: (Jones, Nancy Lee; Redhead, Stephen C.; Sarata, Amanda K.; Smith, Alison M.; Williams, Erin D.);

(New York: 2008), Nova Science Publishers, Inc.

List Price: \$69.00

Reviewed by Benjamin Duskocil

Journal of High Technology Law

Suffolk University Law School

A key issue has recently arisen in Congress amid growing fears of genetic discrimination by employers and health insurers. The debate concerns whether the growing potential for discrimination warrants federal legislation to protect an individual's genetic information.

Genetic Discrimination is a culmination of six individual essays, each addressing one or more aspects of measures put into place to ensure protection of genetic information. Each article presents an informative approach to issues at the base of, and surrounding the Genetic Information Nondiscrimination Act (GINA) while attempting to keep a neutral perspective. However, subtle emissions of support for the proposed legislation can be easily inferred. This review examines the information presented, and seeks to provide readers with adequate knowledge to decide if the book will be helpful and/or enjoyable.

In Chapter 1, the authors explain that "in the context of the current debate in Congress, genetic discrimination can be defined as the potential use of an individual's genetic information by employers or health insurers to discriminate against that individual in employment decisions or health insurance coverage decisions."¹ When scientists completed the first human genome sequence in 2003, the ability to identify genes present in various diseases became a reality.² Many deadly illnesses are now more easily diagnosed and treatable. However, if an individual's

¹ Williams, Erin D.; Sarata, Amanda K.; Redhead, Stephen C., Genetic Discrimination: Overview of the Issue and Proposed Legislation (Leanna J. Albertson ed., 2008 Nova Science Publishers, Inc.).

² Moore, Sharon Wyatt., *Will advances in biotechnology usher in a new era of medicine?* (*Editorial*). *S. Medical J.* 1169, Vol. 96. (2003).

genetic information falls into the wrong hands, it can be used to discriminate against people in health insurance and employment. In response to growing fears of discrimination, the House of Representatives passed GINA.³ However, GINA is still awaiting Senate floor action. GINA would provide greater protections against genetic discrimination by health insurers and employers by extending the Health Insurance Portability and Accountability Act (HIPAA) to further restrict acquisitions and disclosure of genetic information.

In February 2000, on the heels of Congressional rejection of legislation that would have prohibited health insurers from declining coverage or raising premiums based on genetic information, President Clinton issued Executive Order 13145. The order forbade any federal governmental agencies from collecting genetic information on present or future employees, and prevented the use of such information in employment decisions. Clinton declared “we must not allow advances in genetics to become the basis of discrimination against any individual or any group.”⁴ In *Genetic Discrimination*, the authors highlight the early recognition by policymakers of the possible negative impacts of the extensive knowledge available as a result of the Human Genome Project. Such information serves to validate concerns listed by proponents of GINA by underscoring the fact that fears of genetic discrimination have been live for nearly a decade.

Opponents of GINA find the legislation unnecessary. They argue that current legislation in force is adequate to protect genetic information from misuse. Also, opponents contend that the time has not yet arrived for the enactment of the proposed legislation, as supported by the sparse amount of court decisions involving genetic discrimination. Opponents further maintain that genetic information is no different from other health information, finding further legislation

³ Williams, *supra* note 1 (explaining the current posture of GINA). Although H.R. 493 passed on April 25, 2007, by a vote of 420-3, similar legislation, S. 358 has not been put to vote. *Id.*

⁴ National Human Genome Research Institute, *Genetic Discrimination in Health Insurance* (Leana J. Albertson ed., 2008 Nova Science Publishers, Inc.).

confusing and unnecessary. Unfortunately, the book in general provides few arguments asserting that the legislation should not be passed, and does not spend enough time explaining details and reasoning behind such arguments.

Current federal legislation in place regulating genetic information includes the Health Insurance Portability and Accountability Act (HIPAA), the Americans with Disabilities Act (ADA), and Executive Order 13145. HIPAA was passed in 1996 in order to quell growing unrest towards the possibility of genetic discrimination in health insurance. HIPAA establishes rules for eligibility, and protects genetic information that might suggest greater likelihood of acquiring a disease, from being treated as if the actual disease was diagnosed. Furthermore, HIPAA prohibits group health plans from using genetic information in setting premiums or establishing eligibility for the health plan. Proponents of GINA however, criticize current HIPAA regulations, claiming the Act's reach is not long enough to protect citizens from all types of discrimination. For example, the Act does not prohibit group health plans from requiring or requesting genetic testing, and fails to address issues of using genetic information in employment decisions. The door is left wide-open for group health plans and issuers of group health plans to set up premiums and testing in the guise of other legitimate non-discriminatory justifications. GINA is set to address such deficiencies. The book provides an excellent synopsis of each regulation, followed by a brief argument by proponents of GINA as to why each piece of legislation is inadequate.

The book continues the trend of evaluating a current Federal Act, followed by GINA supporters' continued argument for need of greater regulations and protection. The ADA prohibits discrimination against individuals with a disability in employment decisions. Lengthy discussions have been undertaken to determine what qualifies as a "disability." In examining the

ADA, the Equal Employment Opportunity Commission (EEOC) found the definition of disability to consist of three prongs; “(1) a physical or mental impairment that substantially limits one or more of the major life activities of such individual, (2) a record of such an impairment; or (3) being regarded as having such an impairment.”⁵ Under this definition, the EEOC has determined the language to include genetic information relating to disease, or other disorders.

However, although certainly a positive step toward barring discrimination in the employment context, EEOC Commissioner Paul Miller has stated that due to the requirements of the ADA, some forms of genetic discrimination may not be covered.⁶ For instance, an employer would not be barred from requiring or requesting an employee to provide genetic information. Also, no provision prohibits an employer from requesting a genetic test once an applicant is hired if the employer can justify the test by some job related qualifier. Due to the incomplete aspects of federal legislation such as the ADA, proponents of GINA argue that the new Act is necessary to properly protect employers and health insurance agencies.

Also, 32 states have enacted legislation concerning prohibiting genetic discrimination in employment, and 48 states have current laws addressing the use of genetic information in health insurance. By highlighting the emphasis state legislatures are placing on protecting genetic information, the book underlines national recognition of the need to protect individuals from genetic discrimination. Adding to the debate, such legislation varies significantly in both defining “genetic information,” and in the determination of what is protected and prohibited. Furthermore, advocates of GINA stress the fact that due to the supremacy clause, nearly one-third of non elderly insured families and individuals are left without protection under state

⁵ Jones, Nancy Lee; Smith, Alison M., *Genetic Information: Legal Issues Relating to Discrimination and Privacy* (Leana J. Albertson, Ed., 2008 Nova Science Publishers, Inc.).

⁶ Id.

statutes, adding to the need for more broad federal legislation. Again, the book provides proponents with compelling contentions that more strict regulations are needed.

In Chapters 1 and 5 of *Genetic Discrimination*, proponents of the legislation argue that the current legislation in place is inadequate to fully protect individuals from genetic discrimination. In one study, conducted on hereditary pancreatitis, over twenty percent of participants believed that allowing outside access to their genetic test results might lead to discrimination by medical insurers.⁷ In Chapter 5, the National Human Genome Research Institute stated “people have reason to be concerned.”⁸ Public fear of discrimination by employers and insurance companies is well documented. According to a *Time* magazine/CNN poll, 75% of individuals surveyed in 2000 did not want to disclose their genetic information to an insurance company, while 85% of people surveyed in a study by the National Center for Genome Resource believed an employer similarly should not be allowed to view an employee’s genetic information.⁹

This type of statistical information is difficult to brush aside. The negative impact of growing fears of genetic discrimination takes a heavy toll both on the furtherance of medical advances, as well as diagnosis and treatment of the general public for various diseases. As mentioned in chapter 1, if an individual fears that his or her genetic information may be reviewed by a health insurer in setting premiums, the individual will be far less likely to submit to a genetic test.¹⁰ This could bring about the unfortunate scenario where doctors might otherwise discover a gene leading to early recognition of a disease or illness. Proponent’s arguments to

⁷ Williams, supra note 1.

⁸ National Human Genome Research Institute, supra note 4.

⁹ *Id.*

¹⁰ Williams, supra note 1.

enact GINA highlight this very scenario where lives could be lost due to the government's failure to adequately protect its citizens.

On the other side, opponents of the legislation draw attention to facts underscored by advocates of the act. Many employers feel that current legislation is adequate; a belief which is supported by the relatively few documented cases of genetic discrimination. Though promoters of GINA attempt to attribute the low numbers to many unreported cases and individuals' lack of knowledge of such discrimination, they concede the fact that only a small number of such cases have been officially reported. Challengers of the act further argue that new legislation would only create confusion in an area already highly regulated by the federal government. Also, the act's adversaries contend that the cost of enforcing GINA would be considerable and unnecessary.

Genetic Discrimination provides an informative look at the many important aspects and recent developments of genetic information. The book highlights reasons for a pre-emptive strike in the form of the Genetic Information Nondisclosure Act of 2007 to prevent genetic discrimination by employers and health insurers. Each of the six chapters emphasizes the possibility of genetic discrimination due to recent breakthroughs in the identification of genes with specific susceptibility to certain diseases. The essays strive to provide the reader with a complete tour of the proposed legislation, highlighting differences between the Senate and House bills, and listing GINA in its entirety at the end of the book. For helpful guidance, each article contains a concise abstract in order to bring the reader's focus to the important aspects of the writing.

The first chapter provides an excellent introduction to the issue of genetic discrimination by answering a list of common inquiries that an individual without much knowledge of the topic

might ask.¹¹ Described as a “report” within its text, the essay immediately strengthens the reader’s knowledge of the area of law that it addresses throughout the remainder of the book. Covering an array of issues crucial to the examination of GINA, the authors prepare the reader to make informed judgments on whether the reasoning beyond the bill is justifiable. Refreshingly, the article does not leave out opponent’s arguments against enacting the legislation. Instead the authors highlight key arguments and concede statistical data that might disfavor the bill, allowing the reader to form their own opinion. To complete the refined treatise, GINA is broken down by the authors to a more discernable composition by focusing on areas of the bill with the most impact on addressing the discrimination issue. Chapter one is arguably the most complete and informative piece in the book, and does the best job of providing persuasive information on both sides of the argument.

In subsequent chapters, the book continues to lay a foundation of knowledge by addressing different types of genetic testing, as well as highlighting fundamental concepts of human genetics. Chapters two and three supply the reader with considerable knowledge in both the scientific and legal arenas with information presented in an ordered, and understandable style. Chapter three explores current legislation impacting genetic discrimination, analyzing the different statutes’ effect on the protection of individuals from genetic discrimination. In this essay, the authors delve deep into the issues, and revive a focus on arguments by proponents on whether GINA is necessary legislation.

Although informative, the final three essays provide somewhat thinner guidance on GINA’s affect on the business of employer and health insurance companies. Chapter four briefly outlines GINA’s impact on employers, examining the differences in restrictions between the House and Senate versions of the bill. Over twenty pages of table formatted pages follow the

¹¹ Id.

text, comparing the two bills. The sections of GINA are compared under both versions, with the authors emphasizing key differences. Under both versions, the employer's rights to genetic information would be pulled further back, with the House of Representatives bill even protecting information of embryos and a woman's fetus. The fifth chapter in the book gives a comfortable explanation of the issues and concerns related to health insurers' rights to genetic information. One gripe with chapter five is its length. Following a mere three pages or so of text, the essay concludes with the complete transcript of Executive Order 13145. After setting up such an extensive base of knowledge in the first three chapters, the relatively short essays at the end of the book leave the reader feeling a bit empty and searching for more arguments. Chapter six is presented in a similar format to five, addressing the application of GINA to health insurance law. The excerpt gives an informative but again brief explanation of GINA's restrictions on insurers' and employers' acquisition of genetic information.

The information in this book entrusts the reader with a broad understanding of the current issues regarding genetic discrimination and potential implications of future legislation. The impending threat of the misuse of genetic information is certainly real and the reasonable, well informed person would have a difficult task in arguing against legislative adjustments. The Genetic Information Nondiscrimination Act though appropriate, may not be necessary at this time. As explained in chapter 3, relatively few decisions have been made in the courts on the matter. One caveat to this excellent educational work is the need for a bit more explanation and information concerning opponents' arguments. Nevertheless, *Genetic Discrimination* completes its goal by providing the reader with the ammunition necessary to take an informed stance on the issue. High technology and medical audiences from late high school and beyond could comprehensively read this book and in a short time be on the inside of this controversial issue.