

**GENETIC SECRETS: PROTECTING PRIVACY AND  
CONFIDENTIALITY IN THE GENETIC ERA**

*Edited by Mark A. Rothstein.<sup>1</sup>*

*New Haven, Conn.: Yale University Press, 1997.*

*<<http://www.yale.edu/yup/>>*

*Pp. 511. \$45 (hard). ISBN 0-300-07251-1.*

As genetic research continues to provide insights into the blueprint of human life, new possibilities emerge for using the information made available by this research. The ability to extract genetic information from the fundamental biological code empowers us with deeper understanding and novel options, but this scientific progress also raises serious concerns and poses difficult questions. Thoughtful evaluation of the choices we face demands careful consideration of the privacy and confidentiality values inevitably implicated in obtaining, storing, and using the genetic information we can now possess.

In *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Mark Rothstein presents a wide-ranging collection of essays authored by a diverse group of experts who attempt to define and address the issues at stake. This multidisciplinary approach provides the reader with a proper sense of the scope of the debate and encompasses a multitude of viewpoints. Rothstein treats the reader to philosophical discussions, historical studies, and comparative analyses in a variety of contexts. The book should be heralded as an accessible, informative, and provocative contribution to the discussion of the privacy and confidentiality concerns raised by genetic science. However, as a compilation of the works of independent authors, who overlap in their treatment of the topics, the book contains significant repetition. In addition, one seeking policy suggestions will likely find the paucity of such guidance disappointing.

Rothstein divides his collection into six parts: "Background," "The Health Care Setting," "The Effect of New Technology," "Nonmedical Uses of Genetic Information," "Ethics and Law in the United States and Abroad," and "Recommendations." The "Background" section offers a solid foundation for comprehending the discussions following it. Those lacking an extensive education in genetics should not be deterred

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1. Mark A. Rothstein is Hugh Roy and Lillie Cranz Cullen Distinguished Professor of Law, and Director, Health Law and Policy Institute, University of Houston Law Center, Texas.

from reading this book, since Leroy Hood<sup>2</sup> and Lee Rowen<sup>3</sup> clearly explain the science in a chapter accessible to those with a high school biology background. Although the uninitiated reader may extract from this introductory chapter a mistaken sense of determinism regarding genetic events and unwarranted optimism about the progress of genetic research, these impressions should not significantly impact understanding of the ensuing discussion. The chapter does have some weaknesses: the randomness of recombination and relocation of genes is not well expressed, nor is the present status of DNA chip development mentioned.<sup>4</sup>

Another introductory chapter, "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?" by Thomas H. Murray,<sup>5</sup> distinguishes itself as a particularly pointed and pragmatic essay about the nature of genetic information. He argues against "genetic exceptionalism," the treatment of genetic information as different from other types of health-related information (p. 61), and even declares that "it is difficult to claim uniqueness, or even special importance and sensitivity, for genetic information" (p. 65). However, Murray's discussion of the impact of genetic information on familial relationships (p. 65) does not contain the answers to certain familiar questions: What effect would the disclosure of a genetic predisposition for heart disease or breast cancer have on the institution of marriage? What concerns arise if one partner carries a mutation that might manifest itself as a debilitating disease in offspring? Should genetic fitness be a factor in human relationships, a factor that could potentially lead to a world of social eugenics through individual decision-making? While one may accuse Murray of racing to a conclusion, he provides the reader with an understanding of genetic information within the broader context of health-related information.

Part Two, "The Health Care Setting," delves into the dilemmas inherent in preserving privacy and confidentiality in that context. In a

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2. Dr. Leroy Hood is William Gates III Professor and Chair of the Department of Molecular Biotechnology, University of Washington School of Medicine, Seattle, Washington.

3. Dr. Lee Rowen is Research Scientist, Department of Molecular Biotechnology, University of Washington School of Medicine, Seattle, Washington.

4. For background information about DNA chip development, see, e.g., A.T. Woolley et al., *Capillary Electrophoresis Chips with Integrated Electrochemical Detection*, 70 ANALYTICAL CHEMISTRY 684 (1998).

5. Dr. Thomas H. Murray is Professor of Biomedical Ethics and Director of the Center for Biomedical Ethics, Case Western Reserve University School of Medicine, Cleveland, Ohio. Dr. Murray was also a panelist at the *Harvard Journal of Law & Technology's* 1998 Symposium on Privacy, Property, and Family in the Age of Genetic Testing.

care-giving context, one must consider not only the difficult choices themselves but who is qualified to make the decisions: the patient or the health care provider? Should clinical geneticists notify a patient's relatives of a genetic condition that he may possess, even over the objections of the patient (pp. 94-95, 102-03)? In "A Clinical Geneticist [sic] Perspective of the Patient-Physician Relationship," Eugene Pergament<sup>6</sup> explains that, although "[a]rguments for a breach of confidentiality on ethical and moral grounds have been made," such actions by the health care provider would "thoroughly undermine the patient-physician relationship" (p. 95). Concerns also arise out of the competing interests of making genetic information electronically available to medical professionals and safeguarding the vast quantities of sensitive personal information on networked computers (p. 105). Managed care companies will also seek to effectuate their own goal of reducing costs, an objective that stands starkly opposed to protecting patient privacy and confidentiality in many instances (pp. 105-06).

Ellen Wright Clayton<sup>7</sup> describes the current situation for a patient considering genetic testing in "Informed Consent and Genetic Research." She informs us: "In some instances, subjects may be given information that they dare not share with their physician, regardless of their desires. In others, subjects may decide that they are better off not receiving any results at all" (p. 132). Is such a system acceptable? "Genetic Screening from a Public Health Perspective: Some Lessons from the HIV Experience," by Scott Burris<sup>8</sup> and Lawrence O. Gostin,<sup>9</sup> poses perhaps the most difficult question in examining genetic testing at this time. In the current state of medical science, genetic testing permits detection of diseases or the propensity to develop them in instances where medical science lacks the capacity to treat them. "Why test if the consequences are unalterable?" ask critics of genetic testing such as Burris and Gostin. Is this testing likely to do more harm than good through stigmatization, discrimination, and stress? Alternatively, may the knowledge gained aid people in making more informed decisions about how they choose to live their lives? As the authors indicate, the effects are extremely difficult to anticipate (pp. 146-47).

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6. Dr. Eugene Pergament is Professor of Obstetrics and Gynecology, Northwestern University Medical School, Chicago, Illinois; Director of Graduate Program in Genetic Counseling, Northwestern University; and Head of the Section of Reproductive Genetics, Northwestern Memorial Hospital.

7. Dr. Ellen Wright Clayton is Associate Professor of Pediatrics and Law, Vanderbilt University Schools of Medicine and Law, Nashville, Tennessee.

8. Scott Burris is Associate Professor of Law, Temple University School of Law, Philadelphia, Pennsylvania.

9. Lawrence O. Gostin is Professor of Law, Georgetown University Law Center, Washington, D.C.

In the modern world, where reports of computer hacking have become commonplace, placing perhaps the most personal of our possessions — our genetic compositions — in a national data bank rightly causes grave concern. Jean E. McEwen<sup>10</sup> confronts this issue squarely in "DNA Data Banks," the premier essay in Part Three, "The Effect of New Technology." The main justification set forth for the existence of DNA data banks is their forensic value for identifying individuals (pp. 231–32). The federal government, through the DNA Identification Act,<sup>11</sup> has authorized the Federal Bureau of Investigation to implement a national computer network for this purpose (p. 233).<sup>12</sup> Presumably, only law enforcement officials will have access to this data and will use it solely for legitimate law enforcement purposes. However, the best protection of one's privacy clearly would be an absence from the database, raising the issue of whose genetic information *should* be available in a national DNA data bank (pp. 234–36). McEwen explains: "Ultimately, determining who should be in a forensic DNA data bank will require balancing the quantifiable law enforcement benefits that large data banks can confer against the less quantifiable, but nonetheless real, risks to civil liberties that they may implicate" (p. 236). While the high recidivism rates among violent sex offenders (p. 234) may make the decision to include them in the data bank easy, it is not clear at what point inclusion might offend many persons' moral sensibilities or "be invalidated on Fourth Amendment grounds as an unreasonable search and seizure" (p. 234).<sup>13</sup> However, McEwen indicates that perhaps the greatest threat to privacy is not posed by the data bank, which contains relatively limited identification information, but by the retention of the samples themselves, which could be used to gain extensive genetic information (p. 237). How could behavioral geneticists resist attempting to investigate such a fertile source of data (pp. 237–38)?

Perhaps Americans' greatest privacy concerns exist in the social contexts of the workplace and the schools, which are the subjects of

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10. Dr. Jean E. McEwen is Associate Professor, Boston College Law School, Newton Centre, Massachusetts.

11. DNA Identification Act of 1994, 42 U.S.C. §§ 14131–14134 (1994).

12. The national computer network is called "CODIS," an acronym for the Combined DNA Identification System (p. 233).

13. Note, however, that McEwen states:

So far, courts that have entertained Fourth Amendment or other constitutional challenges to forensic DNA data banking laws have consistently rejected them. Even Virginia's data banking law, which encompasses all convicted felons, has been upheld as bearing a rational relationship to the state's legitimate interest in facilitating the investigation of future crimes without suspects (p. 235).

essays in Part Four, "Nonmedical Uses of Genetic Information." In these arenas, the potential harm from revelation of genetic information can be immediate and severe. Mark A. Rothstein<sup>14</sup> and Laura F. Rothstein<sup>15</sup> explore these issues in "The Law of Medical and Genetic Privacy in the Workplace" and "Genetic Information in Schools," respectively. The reader learns that the Americans with Disabilities Act ("ADA")<sup>16</sup> provides the only substantial regulation of genetic information in the workplace environment (p. 287). However, "[i]ts major nondiscrimination strategy is to prevent the unlawful use of medical information" (p. 290) (emphasis in original) rather than to deny employers access to this information. While the Equal Employment Opportunity Commission judiciously applied the ADA to asymptomatic individuals who are genetically predisposed to disease, privacy concerns remain unaddressed (p. 289). "The essence of medical privacy is the right of the individual to decide who, if anyone, has the right of access to the individual's person and the individual's medical records" (p. 296). By permitting unnecessary access to medical records, the statute fails to protect adequately against resulting "embarrassment, stigma, and ostracism" (p. 291).

Laura Rothstein asserts that genetic information might enable schools to provide more appropriate educational environments for particular children (pp. 317-19). However, even her contention that "[h]aving a genetic marker for certain conditions may in theory assist in better measuring students' eligibility for special education and for determining which students should and should not be held to certain performance expectations" (p. 318) appears problematic. Do we really want to decide students' potentials for academic success on the basis of genetic profiles? The author confronts this issue of "labeling and the self-fulfilling prophecy" (p. 322), but the most troublesome possibilities are not discussed. What if ethnic groups have different average genetic measures of intelligence: how will that effect our treatment of individual students? If genetic information about intelligence can be accurately assessed at an individual level, will such insights be used to determine the education that students "deserve" to receive? If genetic bases are similarly identifiable for traits such as sexual preference, speed, and strength, will children's sex education and athletic pursuits be prescribed by genetic indications? If a child has a significant probability (or even a certainty) of developing a fatal condition, will that enter into our educational advising for that individual (p. 324)? Tough questions such

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14. See *supra* note 1.

15. Laura F. Rothstein is Law Foundation Professor of Law, University of Houston Law Center, Texas.

16. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12189, 12201-12213 (1994); 47 U.S.C. § 225 (1994).

as these must be addressed to appreciate fully the potential impact of genetic information in a scholastic setting.

Part Five, "Ethics and Law in the United States and Abroad," endeavors to uncover the morality behind our legal notions of privacy and to engage in a comparative study of American and foreign concepts of privacy, but it regrettably adds little original insight to the discourse. Perhaps these essays merely suffer from their location at the end of a broad examination of the ethical, social, and legal implications of genetic research. In some sense, the diminished marginal utility of the later chapters testifies to the value of the work as a comprehensive inquiry into the challenges to privacy and confidentiality posed by modern genetics.

Mark Rothstein concludes the book with an extensive outline of proposed policy objectives and some advice for implementation in Part Six, "Recommendations." While this section does not offer detailed guidance to the policy-oriented legislator, Rothstein instead lays the foundation for a policy debate by providing a solid broad-based introduction to the privacy concerns implicated in obtaining, storing, and using genetic information. In their attempt to achieve this objective, Rothstein's final article and the entire book excel.

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