GENETICS: ETHICS, LAW AND POLICY
Lori B. Andrews et al.
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TEACHING GENETICS AND THE LAW

The Human Genome Project and related research in the field of molecular genetics have yielded a literal slew of provocative facts and circumstances that will continue to challenge law and public policy for years to come. What is perhaps most extraordinary about this challenge is its breadth: It has cut a wide swath across many important subjects, including intellectual property, discrimination law, privacy, torts, criminal law, gender and family law, conflict-of-interest, and contractual relationships between public and private entities. As a result, countless legal academics, practitioners, and policymakers are sorting out the practical implications and import of these new circumstances. Because much of the research and product development in these fields is taking place in the global arena as a result of multinational public and private collaborations, consideration of genetics issues in terms of conflict of laws, comparative law, and international law also is essential.

Equally interesting and important are the thorny and overarching theoretical issues raised by genetic and genomic science, which have engendered extraordinary interdisciplinary debate in law, ethics, divinity, political philosophy, and public policy. Most prominent is probably whether and how science implicates the notion of free will. That is, will we come to understand that there is after all such

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a thing as "genetic determinism" in some form—as a propensity, for example—so that our common contemporary understanding of the relationship between nature and nurture, biology and the environment, will change and force us to revisit both our construction of humans' real potential for choice and the social policies and practices that correspond with that potential? Also significant is whether the science creates such exceptional problems that new paradigms and doctrines are required to resolve them. For example, are the complex issues raised by the notion of patenting genes and genomes, or by creating clones, truly novel or are they merely the most recent incarnations of old dilemmas, such as whether life and nature in any form (and perhaps especially in human form) are the proper subject matter of private property principles; or whether individuals have a natural or fundamental right (of privacy or human dignity) to conceive (including to mold) and raise children unrestricted by prevailing social dictates? Again, because these questions are unrestricted by political boundaries, their answers are of substantial concern to individuals, business interests, and governments around the world. Accordingly, it is essential to recognize different cultural and political approaches to addressing them and in some cases to reconcile these differences to achieve global interests.

The publication in 2002 of the first textbook in the field was thus most timely. Genetics: Ethics, Law and Policy was developed by three legal scholars. While each one has demonstrated a broad interest in and thoughtfulness toward the range of issues implicated by this field, each is also recognized for his or her significant contributions to certain issues in particular. Lori Andrews, who specializes in bioethics with a special concern for questions relating to women and children, is one of the leading American scholars on the subject of reproductive technologies and reprodogenetics. Maxwell J. Mehlman, a health law expert, has tackled concerns about genetic discrimination and genetic enhancement. Mark


A. Rothstein has done important work in the areas of genetic privacy and behavioral genetics. Because the new genetics appear to pose important and provocative challenges to established legal doctrine in these three areas in particular, their collaboration on this book was especially anticipated.4

To the extent that its intended audience is broad—including, as its authors describe, “not only law students, but students of medicine, public health, and various other disciplines”—Genetics: Ethics, Law and Policy does not disappoint. After a brief introduction, the book begins with a “Scientific Overview” that is essential as background for readers who are not experts in the field. The remaining fourteen chapters cover the most important current issues in the field. Included are an excellent selection of materials on the United States’ own history with eugenics; contemporary genetics research; commercialization of this research; genetic testing and counseling, including access to genetic services and tort liability in connection with these services; gene therapy, pharmacogenetics, and enhancement; the use of DNA to determine paternity and related family law issues; the use of DNA for forensic purposes; behavioral genetics; privacy and confidentiality; genetic discrimination in insurance, employment, and education; and the use of genetics in tort law more generally.6

The “Scientific Overview” chapter lays out in relatively brief form the basics of the field of genetics. It discusses the history of genetic science; the structure of


5. GENETICS, supra note 1, at iii.

6. See id. at xix–xxxii.
DNA; the relationship between and operation of cells, chromosomes, genes, and proteins; genetic differences among individuals; cell division; patterns of inheritance; and the Human Genome Project. Although the 20 or so pages in this chapter might seem far too few to explain a complex field like genetics, further technical explanations are spread throughout the book as they are needed.

This approach spares the reader the task of tackling a long, complicated chapter of technical explanation, and it allows the authors to go into greater detail when explaining the techniques and theory behind specific subjects. For instance, the authors insert a section entitled "How Embryo Stem Cell Research Is Performed" immediately before the infamous "Rabb Memo" that ignited the debate over what type of stem cell research the NIH is authorized to sponsor. It would not be possible for the reader to understand the legal and scientific lines drawn in the Rabb Memo without a basic understanding of the process through which embryonic stem cell lines are created, and the best place for this explanation is directly before the memorandum itself.

The only significant shortcoming of the technical explanations is a scarcity of figures and diagrams. Law textbooks are traditionally void of graphic illustration; however, this textbook details the convergence of the traditional field of law with a scientific field that is best explained with a healthy combination of figures and text. For example, the Polymerase Chain Reaction (PCR) technique is perhaps the single most useful technique in the field of genetics and is difficult for nonscientists to understand based on a sixteen-line description in the text. A graphical illustration of the PCR technique, along with more detailed illustrations in sections where it is employed for purposes such as forensic testing, might bring readers to a fuller understanding of its capabilities and limitations.

The authors choose some writings that raise significant legal issues using somewhat misguided examples. One particularly notable illustration is in the "Commercialization of Genetic Research" chapter, where the authors employ back-to-back articles that deride Myriad Genetics for its patented $2,500 genetic test for breast cancer susceptibility compared to the patented $100 test for Tay-Sachs disease, owned by the Federal government. Although the potential for patent misuse by private companies is an important issue, the book fails to note that the Tay-Sachs test involves the detection of at most eight base pairs of DNA, while the breast cancer test requires the complete sequencing of the very large BRCA1 and BRCA2 genes. These are only details, however, and overall, the

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7. Id. at 15-40.
8. Id. at 135.
9. Id. at 138.
10. Id. at 222.
11. Id. at 223; see also id. at 519-20 (containing a thirteen-line description). PCR is "a technique for amplifying a tiny quantity of DNA into almost any desired amount." Id. at 519.
12. Id. at 518.
13. Id. at 199, 201.
14. Specifically, the $100 Tay Sachs test referred to in the two articles pertains to U.S. Patent No. 5,217,865. It covers methods of detecting two different mutations in the alpha chain of the beta-hexosaminidase gene. One mutation is a single base pair substitution. The other is a medium-sized
book's treatment of the scientific and technical aspects of the subject is quite good and useful.

There are several obvious ways to conceptualize and then to organize the remainder of the materials, including according to the significant "fact patterns" or discoveries and developments, or according to the issues and doctrines implicated by these fact patterns. *Genetics: Ethics, Law and Policy* opts for a less obvious and ultimately more eclectic model, focusing on the uses of the science and its technological applications. Thus, in Part II the book sets out the "Research" uses of the science, including the issues implicated by those uses; Part III describes the "Medical Applications of Genetics" including the issues implicated in that context; and Part IV explores the "Non-Medical Applications of Genetics" which the authors explain are focused on "the use of genetic technologies by social institutions—such as law enforcement officials, courts, insurers, employers and schools."\textsuperscript{15}

This organization is quite useful, because the material is laid out according to how interesting it is as a practical matter to contemporary lawyers, ethicists, and policymakers. The authors give excellent attention to (1) the regulation of genetic research, including human subjects protection;\textsuperscript{16} (2) the commercialization of the genome;\textsuperscript{17} (3) the regulation of and liability for genetic testing, genetic counseling, and gene therapy;\textsuperscript{18} (4) the use of DNA technology to determine parentage, including the special issues that arise in the adoption context; and (5) the use of DNA to identify the perpetrators of crime, including the collection of forensic evidence in DNA databanks and databases. Each of these areas is self-

deletion that occurs near the end of the gene. Both mutations can be detected by analyzing patient DNA samples using oligonucleotides that selectively hybridize to the mutant and normal forms of the gene. In essence, the test covered by the patent involves the detection of a few distinct nucleotides in the gene, the first being the substitution and the second being the first seven nucleotides of the deletion. In contrast, the BRCA1-BRCA2 test sold by Myriad Genetics for \$2,760 and covered by a number of patents (such as U.S. Patent No. 5,710,001 and U.S. Patent No. 6,162,897) involves the full sequencing in both directions of all exons and exon-intron boundaries of the BRCA1 and BRCA2 genes—approximately 35,000 base pairs of DNA are sequenced. In addition, the test includes the specific analysis of five recurrent large genomic rearrangements of the BRCA1 and BRCA2 genes. For scientific reasons based on mutation frequency, the only truly effective way to test for cancer predisposition in BRCA1 and BRCA2 is to completely sequence both genes in every patient. Equating the Tay Sachs and breast cancer patents is thus a classic case of comparing apples and oranges. Indeed, if one were to compare the cost-per-base analyzed by the two tests, the Tay Sachs test would be about \$12.50 per base while the BRCA1-BRCA2 test would be less than \$.08 per base, although this does not take into account the added expense of the genomic rearrangement tests.

15. *GENETICS,* *supra* note 1, at iv.

16. These materials address researchers' conflicts of interest, consent procedures, and special consideration of population and group-based research.

17. Particular issues include patenting of genetic material, the structure of commercial relationships in this area, and the propriety of making biological matter, especially human biological matter, into the subject of intellectual property.

18. Among the topics in this area are regulation of testing products, issues arising in the context of prenatal screening and the screening of older children, access to genetic services, and liability issues implicated in the counseling relationship.
contained, and the selected materials are comprehensive. Because of this coverage, *Genetics: Ethics, Law and Policy* should be given special consideration by teachers across the academy, including in law schools, whose courses are health-related and emphasize the current research and medical applications of the new genetics.

Nevertheless, the book may be less suitable for courses that give relatively equal attention to the areas of law and social policy that are or soon will be implicated by the new genetics or courses that emphasize the social over the medical uses of the science. The two most obvious deficiencies in this respect are the book’s treatment of what Lee Silver has aptly called “reprogenetics,” or the reproductive applications of the new genetics, stem cells, cloning, and germ-line genetic enhancement or genetic engineering; and its treatment of behavioral genetics, which includes provocative issues such as whether there is a genetic basis for criminality, character, and capacity, and if so, whether there are gender or race-based differences in these respects.

In *Genetics: Ethics, Law and Policy*,

19. The remainder of the book focuses on issues that are likely to be of practical interest only sometime in the future and are given correspondingly less weight.


these subjects are addressed in several different places. While their locations are
logical given the structure of the book, this diffusion naturally results in a lack of
any holistic or continuous thematic treatment of the subject—for example,
according to this fundamental rights paradigm—as well as some redundancies.
Perhaps most important, however, the approach also results in sometimes cursory
or misleading treatment of important facts, debates, and law.

Thus, the book first treats reprodogenetics in its discussion of “Research on
Human Embryos.” The authors recognize that society is “deeply divided over
the moral and legal status of embryos,” but they include no materials that probe
the contents of this division. There is only a passing mention of the prominent
national debate (including in the academy, the popular press, and Congress) about
the ethics of using embryos for therapeutic versus reproductive purposes, and the
linked debate about the viability of making distinctions that would allow the
former but not the latter. Indeed, the materials risk creating the false impression
that the law concerning reprodogenetics generally is quite simple and even settled,
when the opposite is in fact true. Of most concern in this respect, the section
contains a federal district (trial) court opinion in the case Lifchez v. Hartigan
purporting to describe the “Constitutional Concerns in Embryo Research.” The
opinion centers on a relatively uninteresting procedural holding that the state
statute in issue, barring research on fetuses and embryos, was void for vagueness.
The end of the excerpted opinion provides a mere glimmer of the real focus of
contemporary constitutional inquiry in this area, namely whether the Constitution
provides a right to experiment on embryos and human reproductive tissue. The
case answers this question in the affirmative—the court rationalizing that this right
is based in the abortion cases. But the book provides no context for this result, no
suggestion that it reflects unsettled legal ground, and no indication of the
important opposing arguments.

The book otherwise treats reprodogenetics in chapters on “Genetic Testing and
Reproduction” and “Gene Therapy, Pharmacogenetics, and Enhancement.” “Gene Testing and Reproduction” focuses on currently available reproductive
technologies, but it also includes an excerpt from an article by Andrews on the
constitutionality of bans on human cloning. Unfortunately, the excerpt is too brief to do justice to this central issue. It summarizes Andrews’s view that the

22. GENETICS, supra note 1, at 131–44.
23. Id. at 131.
24. Id.
25. Id. at 134–35 (citing Lifchez v. Hartigan, 735 F. Supp. 1361 (N.D. Ill. 1990)).
26. Id.
27. The comments after the case suggest that readers look to a later excerpt from an article by
Andrews which contains a response to the general arguments accepted in Lifchez. In our view,
however, the reader should not have to work so hard to find the complete debate and rules that may
apply.
28. GENETICS, supra note 1, at 222–98.
29. Id. at 369–442.
30. Id. at 281–84 (excerpting Lori B. Andrews, Is There a Right to Clone? Constitutional
First Amendment’s “right of scientific inquiry” is not broad enough to encompass cloning research and development. And it provides her analysis of the question whether the Fourteenth Amendment’s right of privacy includes a right to procreate using reprogressive technology. She argues against the frequent assumption (which formed the basis of the district court’s holding that we have just described in Litchman) that such a right is merely the flip-side of the right to choose not to reproduce using technology. However, these materials do not provide the relevant Supreme Court cases, nor do they describe the important opposing perspectives. Indeed, one can easily agree with Andrews’ views—as at least one of us does—and at the same time understand that arguments to the contrary, particularly those of John Robertson, need to be addressed more fully.

The chapter on “Gene Therapy, Pharmacogenetics, and Enhancement” focuses on uses of reprogressive technology to treat illness via somatic cell gene therapy and to tailor drugs to individual needs. There is a brief discussion of controversial “therapeutic genetic interventions that, intentionally or not, affect the genetic material of reproductive cells,” and “genetic manipulation of germ cells or ‘gametes’: the egg and the sperm” to “treat the person’s children.” The debate concerning the use of germ-line gene therapy to remediate disease is well described. However, the fundamental problems of identifying the normal

31. Id.
33. GENETICS, supra note 1, at 281–84.
34. Oddly, this chapter also classifies the use of reprogressive to select a child’s sex or to conceive a matching organ donor as a “Use of Genetics and Reproductive Technologies for Non-Medical Purposes.” Id. at 288–98.
36. GENETICS, supra note 1, at 407.
37. Id.
38. Id.
human baseline and distinguishing between disease and nondisease traits, as well as the much more controversial and difficult question whether germ-line gene therapy should be used for nondisease trait selection, are discussed only briefly, primarily in an article excerpt discussing the legal implications of this use of the technology exclusively in terms of how difficult it would be to police any restrictions and how such restrictions would impede scientific research. The notes following this excerpt are full of references to the meaty issues for law school purposes, such as “if genetic enhancements could improve intellectual abilities, would an enhanced student who did well on an exam deserve an ‘A’?” Still, the absence of materials to guide the classroom discussion of this and related questions is notable.

The other important deficiency that results from the book’s “by uses” approach is the relatively short shrift given to behavioral genetics. “Human behavioral genetics . . . seeks to understand both the genetic and environmental contributions to individual variations in human behavior.” It comprises such provocative and important issues as whether there is a genetic basis for such traits as cognitive capacity or intelligence, aggression or criminality, homosexuality, nurturing, and schizophrenia, whether genetic basis for such traits is likely to lie in single genes or, rather, result from multiple gene interactions, whether the research implicates race and ethnicity as it does in medical genetics research;

39. Id. at 434–38 (excerpting from Jon W. Gordon, Genetic Enhancement in Humans, 283 SCIENCE 2023 (1999)).
40. Id. at 440.
41. Perhaps this section of materials could be assigned in combination with some or all of the later materials on privacy and discrimination, so that the richness of this discussion could be assured.
43. Apart from Rothstein’s work in this area, supra note 41, the two leading volumes in the field currently are NUSSFELD COUNCIL ON BIOETHICS, GENETICS AND HUMAN BEHAVIOUR: THE ETHICAL CONTEXT (2002) (describing the most current state of science concerning the genetics of human behavior including these traits and the implications of these findings for ethics, law, and social policy) and ROBERT PLOMIN ET AL., BEHAVIORAL GENETICS (4th ed. 2000) (describing the field of behavioral genetics, the scientific basis for the view that the source of these traits and others in part lies in an individual’s genes, and the field’s implications for conclusions about nature and nurture).
45. It is certainly controversial and complicated to engage in a discussion of race, ethnicity, and genetics. As the lead author on the recently issued Nuffield Council Report remarked in its Preface: “[T]he subject has an ugly history: within living memory perversely science was put at the service of ideologies that led to the subjugation and extermination of people judged to be genetically ‘inferior’.” NUSSFELD COUNCIL, supra note 43, at v. Aside from this history, there are at least two facets to this discussion that create this difficulty. The first is the argument some have made that race is a genetic rather than a socially constructed category. The second centers specifically on behavioral genetics, and the problem, for example, that certain racial or ethnic groups may be identified by some interpreting the data as being cognitively “superior” or “inferior,” or more or less prone to aggression.

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how the discovery of a genetic basis for such traits implicates our present assumptions about genetic determinism, the role of the environment in the development of human behavior, and thus the “nature-nurture” debate; and finally, how the answers to these questions should affect the development of law and social policy in the relevant areas.

The last three issues are of particular interest to a course in genetics and the law, since their resolutions have potentially vast implications for those areas of constitutional law relating to race, gender, and sexuality, as well as to criminal
law and justice theory, education law and policy, and treatment of the mentally ill, among others. We would expect to engage in substantial philosophical discussions about the meaning of free will, the ways this notion has played out in the law, and whether the discovery of genetic bases for behavior should alter its status.

Despite the awesome significance of these questions, the text’s emphasis on contemporary and practical applications of the new genetics allowed the authors to allocate only 29 pages to their direct consideration; these pages touch only briefly upon the controversial history of behavioral genetics, the methodology used by scientists working in the field, and the (primarily practical) implications for law of a genetic basis for criminality. Of course, many of the conversations about these questions could take place under the rubrics of “privacy” or “discrimination,” which are treated separately. However, this solution (again) requires the student to find the necessary pieces of those conversations’ fabric

49. For example, if a genetic link to aggressive behavior or criminality were established, policy changes might ensue about the criminal law’s fundamental premise of free will and punishment as a basis for incarceration. Discussions also would explore the insanity defense as a model for a defense based on genetically influenced criminality, the efficiency of incarceration for individuals who exhibit this genetic profile, and whether prophylactic medication or even gene therapy might be viable alternatives.

50. For example, if a strong genetic basis for cognitive ability were identified, we would discuss whether public or private schools were entitled to such information to admit or track students and whether institutions of lower and higher education might access and use biological test results in different ways.

51. As the genetic basis for certain mental diseases is further understood, many medical remediation and discrimination issues that would be addressed in the context of criminality and discrimination based on cognitive ability would also take place in this context.

52. The law relies heavily on free will:

"the general presumption in the criminal law is that behavior is a consequence of free will." This presumption is said to “find its intellectual roots in [Emmanuel] Kant’s insistence that moral agency is the central feature of personhood.” According to Linda Ross Meyer, “Essential to [Kant’s vision of] moral agency is the capacity to will, which, for Kant, is to act in accordance with the conception of laws, rather than be passively subjected to forces of nature. Acting in accordance with the conception of laws requires that our thoughts be free, free to follow logic rather than the random fluctuations of brain chemistry, free to make sense.” In the end, this Kantian vision was codified in the law, which as a result, operates on the assumption that liberal society is “a union of reasonable moral agents who respect each other and live under common laws of reason.”

Doriane Lambelet Coleman, Culture, Cloaked in Mens Rea, 100 S. ATL Q.981, 993 (2001) (citations omitted). At the same time, it is understood that the notion is fictional to a large extent, as many factors contribute to the ability to make a truly free choice. Indeed, it has been argued that no one is capable of exercising free will in its purest sense, and still the notion survives in the law. See Matthew Jones, Overcoming the Myth of Free Will: The True Impact of the Genetic Revolution, 52 DUKE L.J. ___(forthcoming 2003).

53. See GENETICS, supra note 1, at 564–68.

54. See id. at 568–71.

55. See id. at 572–89. This decision to give short shrift to issues implicated by behavioral genetics research seems odd since Rothstein and Andrews have devoted significant effort to their consideration. See BEHAVIORAL GENETICS, supra note 41; Lori Andrews, Predicting and Punishing Antisocial Acts: How the Criminal Justice System Might Use Behavioral Genetics, in GENETICS, supra note 1, at 572–74.
throughout the book. Because the behavioral genetics questions are not front and center in those other places, the pieces are not particularly complete.\textsuperscript{56}

The only other important concern we have with the book lies in the authors’ decision to focus almost exclusively on the domestic context in which applications of the new genetics will take place. This is entirely understandable as a logical and practical way to restrict an otherwise unwieldy set of materials. Yet, many if not all of the subjects treated in the book are influenced by both domestic and foreign (including formal international) perspectives and laws, just as the science itself is being conducted both separately and collaboratively in the international arena. The authors recognized the impossibility of de-linking the domestic from the international in the context of what they call the “commercialization of the genome,” which includes an excellent discussion of gene patents and the global and national issues that arise in this context, and as a result this section is particularly comprehensive. While it may have been unworkable (and also unnecessary) to give the same attention to each of the areas addressed in the book, others are also difficult to work with in the absence of their international context. This is true, for example, with respect to reprogenetics. In addition, because genetics research is often conducted across national boundaries, and genetic information is available through computerized databases to researchers and private companies including insurance companies also across national boundaries, it is difficult to conceive of the matter of genetic privacy absent consideration of, for example, European data protection laws and their theoretical and cultural underpinnings.\textsuperscript{57}

Ultimately, our criticisms should only be potentially disqualifying for courses that would give substantial treatment to the areas concerned. Indeed, given the structure of the book and the particular balance struck between current and future applications of the new genetics, this conclusion was foreseeable. The fact that no single textbook can work for all related courses assures that such choices must be made. Based on the compelling need for practical and policy-driven consideration of contemporary applications and their implications, we can only applaud the authors for the home run that \textit{Genetics: Ethics, Law and Policy} is on that front.

\textsuperscript{56} For example, if one were interested in exploring the implications of a genetic basis for cognitive ability and intelligence on education law and policy, one would have to look to the last chapter in the book. Chapter 16, “Other Uses of Genetic Information,” contains a very brief, eight-page discussion of the subject. These few pages do touch upon the essential discussions, such as whether such a discovery should impact policy (\textit{id. at} 747) and whether it is good or bad policy to track children on the basis of cognitive ability (\textit{id. at} 749). However, the space allotted assures that this is only a slight touch without even the room for questions and notes that would suggest alternative (to the excerpt’s authors) perspectives on these matters, or lines of inquiry that would result in the rich discussion that is begged by these issues. The notes and questions that follow the three brief article excerpts and one case included in this section do not follow up on these issues. See \textit{id. at} 755–56.

\textsuperscript{57} The book does include a short excerpt from an article on how the French (and European Union’s) data protection scheme inhibits research, but otherwise leaves this perspective alone. \textit{Genetics, supra} note 1, at 599–601.