ADDRESSING THE EMERGENT DILEMMA OF GENETIC DISCRIMINATION IN UNDERWRITING LIFE INSURANCE


Reviewed by Mahati Guttikonda **

I.

INTRODUCTION: A PROCEDURAL AND SUBSTANTIVE ATTEMPT AT RECONCILING GENETIC INFORMATION WITH LIFE INSURANCE UNDERWRITING

By the end of December 2003, tests existed for more than 1,004 genetic diseases, a number expected to double by 2008.1 Current medical science makes DNA tests for more than thirty diseases possible within a few days of birth.2 Responding to such developments, Mark Rothstein presents a comprehensive examination of the legal and policy implications of using genetic information in life insurance underwriting in his volume of collected essays, Genetics and Life Insurance: Medical Underwriting and Social Policy. Rothstein’s approach to the intersection of genetic information with life insurance is immediately interesting on two fronts. First, he enlists the contributions of a range of professionals and academics, including “a representative of the trade association for life insurance companies, an actuary, an insurance physician, a geneticist, a philosopher, a genetic counselor . . . the president of a genetics consumer organization, a dean and

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* Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy, and Law, University of Louisville School of Medicine.


1. Michael Waldholz, Genetic Testing Hits the Doctor’s Office, WALL ST. J., Dec. 3, 2003, at D1. Many of these genetic tests can be performed at a doctor’s office with a blood test. Id.

professor of insurance law, a trio of comparative law researchers, and an insurance consumer advocate.” 3 Second, Rothstein characterizes the policy responses to the incursion of genetic information to life insurance underwriting as a bilateral management and coordination of procedural and substantive options. 4 By including the viewpoints of a number of professionals and approaching the issue from a consideration of procedural and substantive alternatives, Rothstein presents a meticulous evaluation of the role of genetics in life insurance underwriting. However, Rothstein obviously thought it necessary to include individual essays discussing the current environment of state legislative diversity, the increasing availability of consumer genetics tests, and the reconciliation of morality and policy—he’s work would have benefited had he more closely integrated these themes with his central procedural and substantive proposals.

II. CHOOSING APPROPRIATE PROCEDURAL RESPONSES GIVEN THE STATUS QUO

A. Rothstein’s Suggestions for Procedural Reforms

In his policy recommendations, Rothstein proposes procedural reforms including authorizing insurance commissions to publish annual lists of approved and unapproved genetic tests for use in underwriting; 5 mandating certification for testing laboratories; 6 requiring a licensed physician to make or supervise underwriting decisions; 7 expanding mandatory informed consent to all medical examinations and tests performed in applications for life insurance where no physician-patient relationship exists; 8 requiring life insurers to disclose the medical basis of an adverse underwriting decision; 9 creating a right to appeal an adverse underwriting decision; 10 and prohibiting the use of medical information in underwriting other insurance products or family members. 11 According to Rothstein, “the use of predictive medical

5. Id. at 247.
6. Id. at 247–48.
7. Id. at 249.
8. Id.
9. Id. at 250.
10. Id.
11. Id. at 251.
information” creates three fears in individuals: “(1) the predictions may be inaccurate; (2) the information generated . . . may be used for other purposes; or (3) the predictions will be accurate, but may lead to adverse economic or social consequences.” As a result, procedural reforms are necessary to “establish greater transparency, regularity, and accountability” so that the public is assured that underwriting and pricing are fair.


While Rothstein supplies a number of procedural reforms to confront the reality of increasingly available genetic tests, he is less clear on how these proposals will interact with existing law that differs significantly across states. As a result of the federal McCarran-Ferguson Act, life insurance is regulated by individual states. This allocation of responsibility has borne a mass of varied legislation among the states. On one end of the spectrum are states, such as Vermont, which prohibit the use of genetic testing or information in life insurance underwriting. At the other end of the spectrum are states such as Indiana, which, while prohibiting the consideration of genetic information in health insurance coverage, explicitly exclude life insurance from that prohibition. Between these extremes are a number of ap-

12. Id. at 244.
13. Id. at 245. Rothstein focuses on consumer concerns and rejects the market claim of some in the life insurance industry that procedural reforms are unnecessary since an individual who is declined or offered a policy at a substandard rate can apply at another insurance company. To Rothstein, insurance is distinguishable from consumer products on the market since “the insurance industry is more heavily regulated, life insurance has greater social significance, and the process of underwriting and pricing . . . involves personal . . . and increasingly technical-scientific matters.” Id. at 244–45.
14. McCarran-Ferguson Act, 15 U.S.C. § 1012(a) (2000) (“The business of insurance, and every person engaged therein, shall be subject to the laws of the several States which relate to the regulation or taxation of such business.”).
15. VT. STAT. ANN. tit. 18, § 9334(a) (2000) (“No policy of insurance offered for delivery or issued . . . shall be underwritten or conditioned on the basis of: (1) any requirement or agreement of the individual to undergo genetic testing; or (2) the results of genetic testing of a member of the individual’s family.”).
proxaches. Some states prohibit insurers from requiring an applicant to undergo a genetic test but allow insurers to ask about previous genetic tests.17 Other states permit the use of genetic information in underwriting if such use is based on sound actuarial data;18 informed written consent is obtained;19 written consent is not obtained but sound actuarial principles are applied and notification is provided;20 written in-

17. See, e.g., MASS. GEN. LAWS ANN. ch. 175, § 120E (West Supp. 2004). No insurer, agent or broker authorized to issue policies on the lives of persons in the commonwealth shall require an applicant to undergo a genetic test as a condition of the issuance or renewal of a policy on the lives of persons in the commonwealth . . . . In the provision of insurance on the lives of persons in the commonwealth, a company, or officer or agent thereof, or an insurance broker may ask on an application for such coverage whether or not the applicant has taken a genetic test as defined in this section. The applicant is not required to answer any questions concerning genetic testing. Any application requesting this information must contain or be accompanied by language informing the applicant that the applicant is not required to answer any questions in connection with genetic testing or information as defined in this section and language informing the applicant that the failure to do so may result in an increased rate or denial of coverage. If the applicant chooses to submit genetic information then the insurer is authorized to use that information to set the terms of a policy provided that such information is reliable information relating to the insured’s mortality or morbidity, based on sound actuarial principles, or actual or reasonably anticipated experience. Id.

18. See, e.g., ARIZ. REV. STAT. ANN. § 20-448(E) (West 2002). The rejection of an application or the determining of rates, terms or conditions of a life or disability insurance contract on the basis of a genetic condition, developmental delay, or developmental disability constitutes unfair discrimination, unless the applicant’s medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition, developmental delay or developmental disability. Id.

19. See, e.g., COLO. REV. STAT. § 10-3-1104.7(10)(a) (2004) (“[A]n insurer shall not require the performance of or perform a genetic test without first receiving the specific, written, informed consent of the subject of the test . . . .”); N.Y. INS. LAW § 2612(a) (McKinney 2000) (“No authorized insurer or person acting on behalf of an authorized insurer shall request or require an individual proposed for insurance coverage to be the subject of a genetic test without receiving the written informed consent of such individual prior to such testing, in advance of the test.”).

20. See N.M. STAT. ANN. § 24-21-3(A) (Michie 2000) (“[N]o person shall obtain genetic information or samples for genetic analysis from a person without obtaining informed and written consent from the person or the person’s authorized representative.”). According to § 24-21-3(D), actions of an insurer and third parties dealing with an insurer in the ordinary course of conducting and administering the business of life, disability income or long-term care insurance are exempt from the provisions of this section if the use of genetic analysis or genetic information for underwriting purposes is based on sound actuarial principles or related to actual or reasonably anticipated experience. However, before or at the time of collecting genetic information for use in conducting and administering the business of life, disability income or long-term care insurance,
formed consent is obtained and the insurer pays the cost of the test;\textsuperscript{21} or written informed consent is obtained, the insurer pays the cost of the test, and benefits may not be limited only because the condition is genetic in origin.\textsuperscript{22} In sum, there are a number of permutations of legislative approaches to the use of genetic information in life insurance underwriting.

Some states already incorporate some of Rothstein’s procedural recommendations. In New York and Oregon, insurers are prohibited from incorporating an individual’s genetic test results into the records of that individual’s family members or drawing any inferences about the genetic status of family members.\textsuperscript{23} In addition, in New York an

\begin{itemize}
  \item the insurer shall notify in writing an applicant for insurance or the insured that the information may be used, transmitted or retained solely for the purpose of conducting and administering the business of life, disability income or long-term care insurance.
  
  \textit{Id.} § 24-21-3(D).

  \item If an individual agrees to take a genetic test, the life insurance company or fraternal benefit society shall obtain the individual’s written informed consent for the test. Written informed consent must include, at a minimum, a description of the specific test to be performed; its purpose, potential uses, and limitations; the meaning of its results; and the right to confidential treatment of the results. The written informed consent must inform the individual that the individual should consider consulting with a genetic counselor prior to taking the test and must state whether the insurer will pay for any such consultation.
  
  \textit{Id.} § 72A.139(5); \textit{id.} § 72A.139(7) (“A life insurance company or fraternal benefit society shall not require an individual to submit to a genetic test unless the cost of the test is paid by the life insurance company or fraternal benefit society.”).

  \item An insurer that requests an applicant to take a genetic characteristic test shall obtain the applicant’s written informed consent for the test. Written informed consent shall include a description of the test to be performed, including its purpose, potential uses, and limitations, the meaning of its results, procedures for notifying the applicant of the results, and the right to confidential treatment of the results.
  
  \textit{Cal. Ins. Code} § 10148(a) (West Supp. 2005); \textit{id.} § 10148(d) (“A life or disability income insurer shall not require a person to undergo a test of the person’s genetic characteristics unless the cost is paid by the insurer.”).

  No policy shall limit benefits otherwise payable if loss is caused or contributed to by the presence or absence of genetic characteristics, except to the extent and in the same fashion as the insurer limits coverage for loss caused or contributed to by other medical conditions presenting an increased degree of risk.

  \textit{Id.} § 10148(e) (emphasis added).

  \item No authorized issuer who lawfully possesses information derived from a genetic test on a biological sample from an individual shall incorporate such information into the records of a non-consenting individual who may be genetically related to the tested individual; nor shall any inference be drawn, used, or communicated regarding the possible genetic status of the non-consenting individual.
\end{itemize}
insurer must notify an applicant that an adverse underwriting decision is based in whole or in part on the results of a genetic test. 24 New Hampshire has also adopted legislation similar to Rothstein’s proposal prohibiting life insurers from using genetic information across product lines. 25

Though procedural reforms similar to Rothstein’s proposal have been adopted by some states, it is uncertain that other recommendations can be so easily integrated into consistent state legislation. For example, as part of his recommendation on regulating predictive medical tests, Rothstein recommends that “[s]tate legislatures . . . authorize their insurance commissions to publish annual lists of diagnostic and predictive tests that were approved or not approved for medical underwriting.” 26 J. Robert Hunter, an insurance consumer advocate at the Consumer Federation of America, suggests that a list should be devised by a “scientific body people trust, such as the National Institutes of Health.” 27 Under Rothstein’s approach of allowing review of the list at the state level, different states may approve different tests. 28 Rothstein explains that accepted genetics tests must be reviewed at the state level to avoid problems with antitrust laws. 29 However, he does not explain why the current antitrust law environment must supersede and effectively constrain the “regularity” of underwriting procedures he previously identifies as desirable. 30 If the problem is that lists of accepted genetic tests must be approved on a state-by-state basis be-

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N.Y. INS. LAW § 2612(h) (McKinney 2000); Or. Rev. Stat. § 746.135(4) (2003) (“A person may not use genetic information about a blood relative to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy of insurance.”).

24. N.Y. INS. LAW § 2612(e) (McKinney 2000) (“In the event that an insurer’s adverse underwriting decision is based in whole or in part on the results of a genetic test, the authorized insurer shall notify the individual of the adverse underwriting decision . . . .”).

25. A person in the business of providing life, disability income, or long-term care insurance who obtains information with respect to any genetic testing of an individual or a member of the individual’s family shall not use that information in writing a type of insurance coverage other than life, disability income, or long-term care insurance.


29. Id.

30. Id. at 245, 247.
cause states may have different antitrust laws, why not address the problem at the level of state antitrust laws? A number of states exempt insurers’ anticompetitive activities from their antitrust statutes.

According to Robert H. Jerry II, the collection’s antitrust contributor, statutory immunity of insurers from antitrust laws may remove the specter of antitrust issues. In his suggested procedural reforms, however, Rothstein abstains from addressing in detail the reform of state antitrust laws; such reform would be necessary in order to permit a uniform adoption of accepted genetic tests. It may be that modifying state antitrust laws is unavailable as an option. However, given the nexus between antitrust laws and achieving uniform regulation, the reader unfamiliar with the intricacies of antitrust laws would have greatly benefited from a more detailed analysis of this issue.

Unfortunately, though Rothstein admits that “because life insurance is regulated by states, it will likely be necessary to develop model language or consensus policies to effect a change in every jurisdiction,” he provides no model language for state legislation. And, in view of states’ differing approaches to similar procedural policies, the mere invocation of “consensus policies” provides little administrable guidance. For example, Minnesota and New York require the written informed consent Rothstein recommends. However, each state defines “written informed consent” differently. In Minnesota, “[w]ritten informed consent must include, at a minimum, a description of the specific test to be performed; its purpose, potential uses, and limitations; the meaning of its results; and the right to confidential treatment of the results.” In New York:

Written informed consent to a genetic test shall consist of written authorization that is dated and signed and includes at least the following:

1. a general description of the test;
2. a statement of the purpose of the test;

32. Id. at 211 (citing THE INSURANCE ANTITRUST HANDBOOK: A PROJECT OF THE INSURANCE INDUSTRY COMMITTEE 34-36 (Mark F. Horning & Roger W. Langsdorf eds., 1995)).  
33. Id. at 214.  
34. Policy Recommendations, supra note 4, at 247.  
35. Id. at 241.  
36. Id. at 244–52 (offering general procedural suggestions without reference to actual desirable language).  
37. MINN. STAT. ANN. § 72A.139(5) (West 1999).
(3) a statement that a positive test result is an indication that the individual may be predisposed to or have the specific disease or condition tested for and may wish to consider further independent testing, consult their physician or pursue genetic counseling;
(4) a general description of each specific disease or condition tested for;
(5) the level of certainty that a positive test result for that disease or condition serves as a predictor of such disease. If no level of certainty has been established, this subparagraph may be disregarded;
(6) the name of the person or categories of persons or organizations to whom the test results may be disclosed;
(7) a statement that no tests other than those authorized shall be performed on the biological sample and that the sample shall be destroyed at the end of the testing process or not more than sixty days after the sample was taken; and
(8) the signature of the individual subject of the test or, if that individual lacks the capacity to consent, the signature of the person authorized to consent for such individual.38

Rothstein fails to achieve the level of explication necessary to effect change in a system awash with numerous options for the same general procedural reform. However, the value of Rothstein’s work remains inasmuch as it presents a comprehensive survey of procedural reforms from a range of experts. Proposals include increased protection of consumer medical information and research data;39 requirements that underwriting on the basis of genetic information and tests be rooted in sound actuarial principles;40 acquiring genetics expertise regarding ordering and interpreting genetic tests;41 and the creation of an oversight body to regulate and approve genetic tests and ensure consumer rights and privacy.42

38. N.Y. INS. LAW § 2612(b)(1)–(8) (McKinney 2000).
40. See Meyer, supra note 39, at 32.
41. Wendy R. Uhlmann & Sharon F. Terry, Perspectives of Consumers and Genetics Professionals, in GENETICS AND LIFE INSURANCE: MEDICAL UNDERWRITING AND SOCIAL POLICY, supra note 3, at 147, 167.
42. See Knoppers et al., supra note 39, at 191; Hunter, supra note 27, at 224–25.
III. SUBSTANTIVE SCHEMES AS A REFLECTION OF SCIENCE AND POLICY

A. Rothstein’s Substantive Recommendations

Rothstein recommends substantive measures, such as prohibiting offering policies at preferred rates based on genetic information. For example, if companies were allowed to offer discounts to applicants found to be free of harmful mutations after being administered a particular battery of genetic tests, low-risk individuals would flock to those companies. As a result, companies not offering preferred rates would be forced to raise rates for all individuals or use similar genetic testing to weed out higher-risk individuals. In effect, an adjustment in pricing structure might occur even if it is based on an underinclusive and under-informative battery of tests and thus not justified by science.

Rothstein also recommends prohibiting the use of predictive medical information in underwriting group life insurance policies but allowing it for individual policies. Rothstein’s recommendation is consistent in that predictive testing would not be prohibited in buy-up arrangements for late entrants, reentrants, or individuals wishing to increase their coverage above the base level. Finally, Rothstein suggests that high-risk pools, subsidized, for example, by low-risk individuals or taxpayers, be established to provide high-risk individuals the opportunity to purchase life insurance at affordable rates. Rothstein’s fundamental recommendation, however, is that no genetic-specific laws which treat genetic information differently from other medical information be enacted, since science does not support such a clear distinction between genetic and non-genetic diseases.

43. See Policy Recommendations, supra note 4, at 258.
44. Id. at 257–58.
45. Id. at 258.
47. Id. at 259. Rothstein justifies this differential treatment by pointing out that group policies have lower coverage amounts and groups, like employee groups, are motivated for reasons besides obtaining life insurance. Id.
48. Id.
49. Id. at 260.
50. Id. at 243 (“It is clear that both genetic and environmental factors are involved in virtually every malady.”).
Several of Rothstein’s substantive recommendations incorporate the suggestions made by the other professional essayists in his book. The recommendations, however, are not as interesting as the less fully addressed issues of the burgeoning private genetic test industry, morality, and public policy. The latter issues are included in essays by other professionals in the collection but Rothstein fails to speak much to these issues in his own substantive recommendations.

B. The Import of Science in Determining Legislative Policies

As previously mentioned, there are genetic tests to determine predisposition for over 1,000 diseases, including breast cancer, colon cancer, melanoma, heart disease, osteoporosis, immune dysfunction, cystic fibrosis, and early-onset Alzheimer’s. Genetic testing has also been proposed for “behavioral disorders such as alcoholism, mania-depression, and even ‘risk-taking’ behavior.” An increasing number of private companies sell health-related genetic testing directly to consumers over the Internet; in fact, at least fourteen websites offer such services. Commercial tests may be of limited use to underwriters in ensuring that they are adequately informed about an applicant’s health status since commercial genetic test companies tout the confidentiality of their results. Though he admits that “[h]ome collection genetic test kits are available for several genetic disorders, and increasing availability of testing outside of the clinical setting suggests that at-risk individuals can learn their genotype in off-record testing,” Rothstein does not consider how these changed circumstances can be incorporated into substantive responses to the problem.

While they address the situation in which insurers have or can have knowledge of an applicant’s medical state, Rothstein’s substantive suggestions could have explored further the implications of situations where consumers can keep certain facets of their medical

51. See, e.g., Meyer, supra note 39, at 45 (arguing against genetic-specific laws); Norman Daniels, The Functions of Insurance and the Fairness of Genetic Underwriting, in GENETICS AND LIFE INSURANCE: MEDICAL UNDERWRITING AND SOCIAL POLICY, supra note 3, at 119, 143 (same); Uhlmann & Terry, supra note 41, at 169 (recommending a system ensuring coverage for all); Knoppers et al., supra note 39, at 191 (arguing against genetic-specific laws); Hunter, supra note 27, at 228 (suggesting guaranteed life insurance for all).

52. See Waldholz, supra note 1.

53. See id. See also Naomi Freundlich, Genetic Predictions: Just a Swab Away, N.Y. TIMES, Mar. 21, 2004, § 3, at 8.


55. Freundlich, supra note 53 (citing 2003 National Institutes of Health study).

56. Id.

57. Policy Recommendations, supra note 4, at 240.
histories confidential. Rothstein confines his response to emerging private genetic tests, suggesting that adverse selection\textsuperscript{58} may not necessarily occur because consumers must decide to withhold negative results, and “[s]ome level of adverse selection” may already be priced into the insurance.\textsuperscript{59} A similar response to this problem—expanding the latter argument—was suggested by Wendy McGoodwin, executive director of the Council for Responsible Genetics:

[Population-wide risks of genetic conditions are already reflected in the actuarial tables used by insurers to establish rates. It is therefore misleading for insurers to suggest that their financial solvency will be jeopardized if they are obligated to insure people who are at risk for genetic conditions. In fact, insurers have always insured people who are at risk for genetic conditions. Previously, however, it was not possible to identify those people at risk for genetic conditions before they became ill with the disorder.\textsuperscript{60}]

This argument may provide a compelling answer to the concern that the use of home and commercial genetic tests will lead to adverse selection by consumers. That is, even though insurers may have asymmetrical information as people initially rely on home and commercial genetic tests, eventually the increased riskiness of the insured will become incorporated into actuarial tables. McGoodwin argues that Rothstein’s claim that “some level of adverse selection” is included in actuarial tables is sufficient, rendering the use of genetic underwriting in life insurance unnecessary. Indeed, for certain diseases, the incorporation of genetic risk into actuarial tables may take years or decades. However, given the continual evolution in the field of genetics, this gradual incorporation may be a better option than a more costly one involving the industry and state legislatures responding to daily scientific developments. Due to the environment of scientific change, it may have better suited Rothstein to devote more attention to explaining this theory of a continuous inclusion of genetic information in actuarial statistics. The reader here is left to wonder why, if only “some level” of adverse selection is priced into insurance, Rothstein has not expounded other, more specific ways to confront the use of consumer genetic tests by individuals.

\textsuperscript{58} As defined by one contributor to Rothstein’s work, adverse selection occurs when “[a]n individual who knows he or she is going to be sick or die prematurely [has] a strong incentive to purchase new or larger amounts of insurance than he or she would have otherwise.” Meyer, supra note 39, at 29.

\textsuperscript{59} Policy Recommendations, supra note 4, at 240–41.

\textsuperscript{60} Wendy L. McGoodwin, Genetic Testing in Life and Disability Insurance: A New Challenge for Public Policy, The Brief, Fall 1998, at 24, 29.
C. An Unaddressed Moral/Public Policy Question

In his substantive recommendations, Rothstein should have devoted more attention to the moral and public policy concern of insurance as a basic need. While in the United States the debate “centers on genetics and access to health insurance,” in many European countries life insurance “is seen as a basic socioeconomic good, a right, not a privilege.”61 This viewpoint has allowed European countries to adopt policies such as a ceiling under which amount underwriting for life or disability insurance will not utilize genetic tests.62 Rothstein concludes that such an option is not viable in the United States because it would require a clearly articulable definition of “genetic”; an individual determination that a person was not abusing the system by purchasing multiple policies each below the maximum; and an adjustment in pricing.63

These practical considerations are indeed relevant, but it is rather disappointing that Rothstein fails to discuss, in the context of his substantive recommendations, any moral or public policy justifications, since they have been the motivating forces for structuring the insurance system elsewhere in the world. This is especially true given that Rothstein considers the issue important enough to include in the collection an essay by Norman Daniels, Professor of Ethics and Public Health, suggesting that life insurance may have a social function, beyond individual risk management, of “keeping people at an adequate standard of living.”64 While Daniels admits that the moral case for life insurance may not be as solid as for health insurance,65 the argument that medical, life, and disability insurance all serve the same function of providing “a safety net to families in times of crisis” also exists.66 Regrettably, Rothstein claims that “[l]ife insurance is regarded by the public as less essential than health insurance, and therefore less sweeping regulatory intervention is likely,”67 without approaching the moral issue at all. Rothstein’s substantive recommendations would have been more complete if he had included an appeal to the moral question, or at least offered a more in-depth discussion of its dismissal.

61. Knoppers et al., supra note 39, at 173.
62. Id. at 181, 186, 187.
63. Policy Recommendations, supra note 4, at 257 (citation omitted).
64. Daniels, supra note 51, at 144.
65. Id. at 136 (“We have nothing matching the argument from equality of opportunity that was key to showing why medical insurance should not be governed by the risk-management view.”).
67. Policy Implications, supra note 4, at 261 (citation omitted).
IV. Conclusion

Rothstein presents an easily understandable, comprehensive survey of an area of law and policy with complex scientific, public policy, economic, and legal dimensions. The value of the work is significantly enhanced by the inclusion of a number of perspectives from professionals in fields inevitably connected to the debate of the use of genetic information in life insurance underwriting. While it is true that the work could have included more about the integration of policy in current legislation, the role of private consumer genetic tests, and the moral justifications of policy choices, *Genetics and Life Insurance* is nevertheless an excellent source of in-depth information on an issue which has caught the attention of legislatures, insurers, scientists, and the public. Rothstein’s work will have a significant impact on each of these groups in the near future.