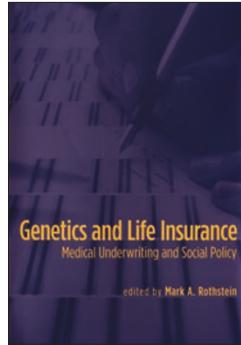


## Secrets of life, wagers on death



### **Genetics and Life Insurance: Medical Underwriting and Social Policy**

**Edited by Mark A Rothstein**

The MIT Press, 2004  
304 pp. hardcover, \$34  
ISBN 0-26218-236

**Reviewed by Roberta M Berry**

*Genetics and Life Insurance* considers the policy implications of a set of unintended consequences at the intersection of genetics and life insurance: consequences that threaten to slow the progress of the genetic enterprise in its quest for cures or to undermine the viability of the life-insurance market. The volume is aimed at the concerned citizen and policymaker, as well as those with expertise in genetics or in life insurance; it will be largely accessible to expert and nonexpert alike.

The book succeeds admirably in illuminating the issues and advancing the policy debate. The contributions are of high quality and their order of presentation ensures that the issues emerge in sharp and nuanced detail. The animating spirit of the book expects that individuals will continue to dispute the facts, their ethical importance and their policy implications, but that the political community can make headway in addressing practical problems that confront us despite, and in part thanks to, this continuing discord and the debate it generates.

The opening chapter draws on survey results to frame the questions that the book explores. The next four chapters develop a portrait of life insurance as an invention that permits us to mute somewhat the impact of premature mortality by transforming our present vitality into future financial support for our dependents. To persuade an insurance company to enter into a contract for individual life insurance, an applicant must disclose information that enables the company to predict longevity: age, gender, family history, test results. Most applicants are offered life insurance at preferred or standard rates, but some are charged extra-risk rates or refused coverage altogether; in 2000, 5% of policies were issued at extra-risk rates and 4.3% of applications were declined.

These small percentages translate into large numbers of individuals, and with the rapid expansion of genetic testing, many are concerned that the numbers could grow. But negative test results can dispel health concerns raised by family histories, and positive results increasingly will allow individuals to undertake treatments or lifestyle changes that will render them insurable. And if we allow applicants to withhold genetic information that does indicate increased risk, a company may well assign them to lower risk

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classes than their actual risk warrants. The company will then face the prospect of claims that are inadequately supported by premiums. The company might raise premiums across the board in an effort to right the ship, but this will only send low-risk individuals to other companies where coverage can be had for less, and the ship will list ever more dangerously as an ever riskier group of individuals is left behind. Eventually, this process of adverse selection may conclude in the financial collapse of the company or, if the problem is spread relatively evenly across companies, the entire market may suffer. It is only fair, then, that all, including the genetically unlucky, divulge their secrets and pay their fair share in light of their risk. If some are too risky to be offered coverage—or offered coverage that is affordable to them—a publicly financed safety net or some other approach that does not threaten the viability of the life-insurance industry should be used.

Challenges to this portrait as well as additional perspectives on the issues appear in the next five chapters, in contributions authored by a philosopher, a genetic counselor and the president of a genetics consumer organization, three comparative law researchers, a law dean and professor, and a consumer advocate. The philosopher's contribution disputes the portrait's assumption that actuarial fairness—charging premiums pegged to riskiness—constitutes moral fairness. The medical underwriting practices of life insurance companies should be assessed, he argues, by reference to the social function of life insurance, providing support to dependents in the event of premature death, rather than by reference to the mechanics of an efficient risk-management marketplace.

The genetic counselor and the president of a genetics consumer organization present evidence that some life insurance companies have used genetic information in ways that are not actuarially justified. They also note widespread fear of loss of insurance in consequence of genetic testing and report the ways in which individuals at genetic risk and genetics professionals currently are coping with this.

The contribution by three comparative law researchers surveys and assesses the range of approaches taken to these issues in Europe, Australasia and Asia, which include comprehensive prohibitions on the use of genetic information as well as more limited, insurer-initiated moratoria, sometimes tied to a ceiling on the amount of life insurance that may be purchased without supplying genetic information.

The law school dean and professor of insurance law examines the possibilities for collaborative action by insurance companies in the US against the backdrop of federal and state antitrust law. The intricate antitrust regulatory structure, and the uncertainties that it generates, are sketched in vivid strokes. The author concludes that governmental intervention rather than collaborative insurer action is the realistic route to regulating the use of genetic information, assuming such regulation is warranted.

The book concludes with the editor's policy recommendations. His discussion and recommendations will be comprehensible to those who have read the contributions, if not necessarily persuasive—although this reader found them so.

We share a common interest in addressing mortality, forestalling it by advances in genetics and coping with its financial impact on our dependents by life insurance. This book is an excellent contribution to navigating our way to policy solutions that acknowledge and advance that shared interest. ■