

GENES AND INSURANCE: ETHICAL, LEGAL AND ECONOMIC ISSUES[†]

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The advent of cloning, the completion of the human genome project and stem cell research have recently occurred in a society ill-prepared to administer or regulate them. Immediate responses from policy makers vary from outlawing allegedly immoral practices to embracing potentially life-saving research. The difficulty faced by legislators is largely one of foreseeing the impact of significant scientific advances on society. Policy makers thus search to create laws that help society without accidentally generating ethical nightmares. Inevitably, there is a great time lag between technology and legislation.¹

Contemporary advances in the field of genetics are examples where technology is proving to be increasingly influential. Genetics may hold the key to predicting the onset of disease and prospective health problems. Of course there is no guarantee that such advances may come about. Nonetheless, it would be a daring soul who declares such conclusions impossible. These potentially predictive qualities may help individuals better plan a lifestyle so as to accommodate unfortunate future dispositions. However, genetics' prophetic potential is not merely of interest to the individual. Health and life insurance companies would surely endeavour to use genetic information to reassess risk and premiums.

What is so special about the advent of genetic technology? Previous medical breakthroughs and procedures have altered risk assessment in the past. New treatments, improved analysis, superior prediction and prevention of disease have all influenced insurance companies' calculations of premiums. However, that genetic information may be unique in its potential to identify individual health concerns has fueled an unprecedented amount of speculation. Obviously having certain genes does not mean that one's health is entirely pre-determined. Environment and lifestyle choices play a fundamental role. Still, genetic knowledge may soon be a revealed and dependable factor that contributes enormously to forecasting an individual's future health.

As exciting as these advances seem, problems become apparent when considering the repercussions of readily available genetic information. Should an individual, possessing genes signalling the onset of Hodgkin's disease, have a right to keep this information private? Can he remain ignorant of his condition should he so desire?

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[†] Marcus Radetzki, Marian Radetzki and Niklas Juth, *Genes and Insurance*, Cambridge University Press (2003).

¹ See generally Judith Areen, Patricia A King, Steven Goldberg, Lawrence Gostin and Alexander Morgan Capron, *Law, Science and Medicine* (2nd ed, 1996).

Should an insurance company be privy to such information? If so, what would the justification be — on social policy grounds — for charging higher premiums to a person already subjected to grave health concerns? Conversely, how could insurance companies expect to survive should persons with knowledge of potentially troublesome health issues purchase extensive policies at low premiums? What happens to those unable to obtain insurance? These questions are not novel, yet the impending augmentation of health information via genetic knowledge will provide necessarily more concrete answers.

Genes and Insurance: Ethical, Legal and Economic Issues is an example of the powerful contribution policy books can make towards solving these complex issues. Its concise and powerful reasoning guides us through a minefield of uncertainty, and although predictive books are by nature speculative, the arguments and conclusions here are convincing. The guidance is readable and colloquial and the authors do their best to ensure that the reader does not get lost in the more contentious points. This is no better demonstrated than in the authors' provision of summaries at the end of every argument. This graduated process allows a reader simply to read and be guided by rather than having to study the text and re-read the more complex arguments.

Unfortunately, from a lawyer's perspective, the book's policy approach cannot be, nor does it purport to be, an authoritative legal review of this field. Legislative references are used minimally to illuminate points. No cases are cited to elucidate the present approach of the courts. Rather, emphasis is placed on issues of public concern and practical significance.

The book is divided into four parts.

PART I

After an introduction to the general topic of genes and insurance, the authors present a crash course in elementary biology, a chapter largely unnecessary for those familiar with the basics of biology and DNA. For the novice, the chapter arms the reader with an ability to understand some basic science in the field, which may prove useful for comprehending genetics and its potential. From this the authors discuss the limited impact of genes on the onset of disease, pointing out that there are many other contributing factors such as damage to RNA and proteins. Although genes are hugely important, they are by no means the only factors in determining future health.

The authors are to be given credit for the ordering of this book. The presentation in later chapters is not dependant on an understanding of the biology involved. That discussion is also not predicated on complex ethical considerations mentioned later. This allows the reader to choose their immediate interests; references are clearly made to other areas of the text where conclusions are founded on earlier points.

PART II

Next, the authors guide us through the history of medical insurance and discuss the different stances adopted and problems faced by various countries, along with the initiatives they use to confront these concerns. The chapter is important: the authors' prediction of an exodus from social welfare to privatised health care is all too convincing. Focus is primarily on Sweden, Norway and Denmark, but the issues raised relate to most North Atlantic countries. In the United States, most people prefer private medical care; there have been repeated, unsuccessful efforts to create national health insurance.²

The potential for genetic information to destabilize these insurance systems is then demonstrated. Insurance is a response to risk and most persons choose to transfer the risk of financially burdensome illness to the insurer.³ The authors point to problems of asymmetric knowledge where private use of home tests would allow a client to acquire more information about their health status than could an insurer. An individual could then organise policies with an insurer to cover potential health care costs, leaving the insurance industry at a grave disadvantage. Such continued developments could lead to the collapse of the insurance industry. For all its faults, the industry is vitally important as it protects our opportunity to pursue life goals, reduces pain and suffering, prevents premature loss of quality of life, and provides valuable information needed for life planning.⁴

The authors next demonstrate that the effects of the new world economy may see a movement of insurance companies from overseas. Regulating and forming overseas contracts with the public would allow circumvention of regional legislation. An analysis of the present situation illuminates the deficiencies of simply trying to pass laws to restrict these practices. The authors also raise the possibility of a new and potentially troublesome scenario — the emergence of genetic prejudice and even a possible separation of society into genetic classes.

PART III

Part three commences with an in-depth discussion of the ethical issues involved in genetics and insurance. A problem with this is that — through no fault of the authors — presenting the ethical arguments requires an introduction to many views from a wide range of ethicists. These chapters are essentially a lengthy ethical discussion with an application to the issue of genetics and insurance where possible. I must admit I had trouble absorbing this material despite having covered it previously in my academic studies. To be fair, the authors warn that readers may have trouble with the concepts if they are not familiar with ethical arguments beforehand. Unfortunately, it is all but impossible to simplify some ethical

² *Ibid.*

³ Congressional Research Service, *Insuring the Uninsured: Options and Analysis* (1988) 12-17.

⁴ Dan W Brock and Norman Daniels, 'Ethical Foundations of the Clinton Administration's Proposed Health Care Systems' (1994) 271 *Journal of the American Medical Association* 1189.

arguments to make them more digestible for the novice reader. The authors' effort in this respect is commendable.

In fields such as ethics — as opposed to earlier discussions of policy and insurance — it is more difficult to draw solid conclusions and easier to raise objections. The authors do manage to formulate a convincing conclusion, one favouring a regulatory approach that denies insurance companies access to genetic information. The ethical discussion concludes that no individual should be left without access to goods that are vital for welfare simply due to genetic makeup. This argument considers insurance to be an instrument of social policy, not a venture existing solely for profit.⁵

PART IV

The book concludes with the authors' solutions for the impending crisis — either a return to social welfare or an introduction of a government-funded entity to insure those who are too risky for other companies. This is a solution with which, after reading this book, I agree. In the authors' view, it is important to look at the problem on the basis that equality is a right.⁶ I have to admit that I did not agree with each argument presented, and I differ in my personal views from some of the authors' ethical conclusions. However, the most important realisation I had while formulating my objections was that most of my arguments were based on the information and clear reasoning the authors themselves provided. While a reader may disagree with some of the authors' conclusions, I am confident that this book will give its audience a capacity to discuss and debate these issues in depth.

⁵ Areen, King, Goldberg, Gostin and Capron above n 1, 777.

⁶ Charles Fried, 'Equality and Rights in Medical Care' (1976) 6 *Hastings Center Reports* 29.