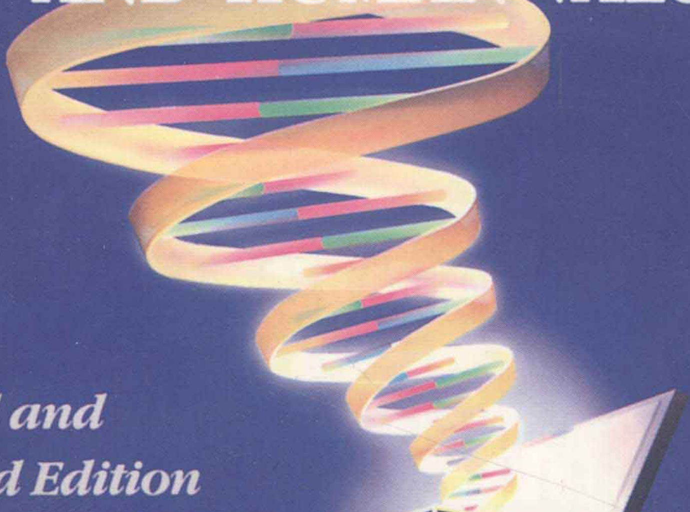
GENETHICS

THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES



Revised and Updated Edition

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THE ETHICS OF ENGINEERING LIFE

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To Tara Elizabeth Cullis for her constant support and faith.

D.S.

To Annette Desmarais, a co-conspirator in my life, and to my parents, Ruth and Kenneth.

P.K.

PREFACE

Genethics is an exploration of the clash between modern genetics and human values. Designed to be accessible to nonscientists, it is both an introduction to the underlying biological principles of the new genetics and a search for unifying ethical themes that can help individuals navigate through the uncharted, often treacherous waters of genetics and morals. The title itself is a novel, "recombinant" word that splices the words "genetics" and "ethics" together to capture their conceptual inseparability.

Despite the undeniable complexities of the ethical issues surrounding modern genetics, we believe that it is possible to offer lay readers something more than another scholarly treatise of agonizing pros and cons or the highly technical musings of scientists. Instead of presenting one more account of the seemingly irreconcilable moral dilemmas arising from genetics, we propose a number of concrete moral "solutions."

Genethics represents a search for broad, lasting moral guidelines — gleaned from complex, real-life ethical issues in genetics — that are at once imaginative, humane and scientifically sound. These moral guidelines, or genethic principles, as we call them, are not intended as final answers to every problem. On the contrary, we offer them as provisional answers that can at least serve as a scaffolding for more meaningful and precise answers that may emerge during the decades of scientific discovery that lie ahead.

For this reason, we make no pretense that our moral arguments are completely objective. The genethic principles we present embody a distinctly humanistic point of view — one that we believe is shared by many thoughtful scientists and nonscientists. *Genethics* differs dramatically from other books on the topic by replacing abstract philosophical debate of moral pros and cons with scenarios or case studies designed to serve as scientific parables, each selected to reveal the single genethic principle that is the organizing principle of each chapter.

In our fragmented society, the power to apply new scientific knowledge tends to reside not in the individual but in vast corporate and military organizations that possess the resources and expertise to harness novel techniques. In our view, motives of profit and military power should not be allowed to shape our society's technological priorities. By providing a foundation of scientific understanding, *Genethics* sets out to empower ordinary people — many of whom understandably tend to shy away from science — to make their own ethical choices in genetics. Everyone must share responsibility for the decisions that will increasingly shape the genetic future of our planet.

Molecular genetics is by nature an incredibly complex subject. And we realize that — despite our best efforts to render some of its subtleties understandable to the vast majority of people who have had little or no university-level training in the life sciences — our decision to refrain from condescending or cartoonish descriptions of intricate hereditary processes might make portions of *Genethics* difficult for some. To minimize frustrations, it is important that readers grasp the basic organizational plan of the book.

Genethics includes an introduction and 14 chapters. The introduction presents a personalized vision of the limits of science and the proper role of scientists in modern society. The first five chapters of the book are intended to serve as a short course, or primer, on selected principles of modern genetics that underlie the discussions of ethical issues in the remaining chapters.

While we strongly encourage a careful reading of these preliminary chapters, we suggest that readers who find themselves bogged down in this section should not hesitate to pause, place a marker at that page and proceed directly to the less technically demanding ethical discussions beginning with chapter 6.

Chapter 1 offers a panoramic view of the history of genes — their primal role in the origin and evolution of all life on earth and in human attempts to make sense of often invisible hereditary mechanisms.

Next, in chapters 2, 3 and 4, we focus on the biological processes by which genes carry out their functions at the molecular, cellular and population levels. We view the activities of genes through the metaphor of dance — as elegant, exquisitely ordered, almost ritualized patterns of movement in space and time.

At the highest level of magnification — beyond that of the most powerful electron microscope — the gene's dance might be called a molecular dance, as genes orchestrate the orderly synthesis of molecules essential to the life processes of the cell and transmit replicas of themselves to the next generation of cells. At the next lower level of magnification, a gene's dance could be called chromosomal, in reference to the ritualized, visually symmetrical movements during cell division of the gene-bearing bodies known as chromosomes. Finally, from a more distant perspective, a gene might be seen to dance to an evolutionary beat — over geologic time and across great geographic distances in populations.

The last primer chapter, chapter 5, describes selected techniques in genetic engineering that have only recently allowed our species to "choreograph" the dances of individual genes to satisfy our own real or perceived needs.

Each of the eight chapters making up the second part of *Genethics* is designed to serve as a genethic parable — an independent search for a unifying moral imperative within a single crucial area of human responsibility for genes. Together, they represent the first fruits of our search for humane, broadly applicable ethical themes in genetics concerning issues such as genetic screening, gene therapy, biological weapons, environmental damage to DNA, crossing evolutionary boundaries, genetic diversity and genetic maps. While most readers will read these chapters in sequence, they could, in principle, be read in any order.

Finally, the epilogue offers a brief review of the moral themes presented in *Genethics* and offers suggestions for expanding our search for new, more meaningful genethic principles to guide us in the years ahead. Throughout the book, scientific and technical terms appear in italics on first mention and are defined in the glossary at the end of the book. A list of suggested references for each chapter is also included at the end of the book.

We express gratitude to those scientists who took time from busy schedules to engage in freewheeling preliminary discussions of the themes presented in *Genethics*. They include: George Wald, Harvard University; Stephen J. Gould, Harvard University; Jonathan Beckwith, Harvard Medical School; and David Baillie, Simon Fraser University. Special thanks go to Jan Kraepelien and Annette Desmarais for their support and for thoughtful conversations on this topic extending back many years.

The following reviewers generously offered their expertise during the revision process: Jonathan Beckwith, Harvard University; Milton Gordon, University of Washington; Harold Kasinsky, University of British Columbia; Jack Keene, Duke University; Richard Palmiter, University of Washington; and R. C. von Borstel, University of Alberta. While the contributions of these and others to *Genethics* were invaluable, we take full responsibility for the accuracy, content and viewpoints expressed in this book.

Finally, we gratefully acknowledge the efforts of our excellent editor, Nancy Flight, for her painstaking attention to detail without sacrificing the spirit and occasional stylistic leaps of this book. Thanks also to the staff at Stoddart Publishing Company for their steadfast support for this undertaking. We also express our thanks to the staff of the Woodward Library at the University of British Columbia and at the Hastings Institute of Society, Ethics and Life Sciences, Hastings-on-Hudson, New York, for their assistance. A portion of the research and writing of *Genethics* was funded by Government of Canada: Science Culture Canada Program, and the Ontario Arts Council.

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INTRODUCTION

Scientific Explosion

Newspapers and magazines regularly announce the latest developments in science and technology — surrogate mothers, the greenhouse effect, the strategic defense initiative, gene transplants, PCBs, dioxins, artificial intelligence, extraterrestrial intelligence. The familiarity of these arcane terms reflects the extraordinary power of science and technology in shaping our lives and society today. This power is a very recent phenomenon. In fact, from invention to widespread application, the entire history of such revolutionary technologies as automobiles, airplanes, antibiotics, telecommunications, nuclear energy, space travel, computers and oral contraception is encompassed within the span of a single human life.

The application of scientific discoveries and inventions has brought spectacular improvements in our health, material wealth and comfort in a remarkably short period of time. Yet immense global problems such as pollution, overpopulation, the proliferation of nuclear arms, the extinction of numerous species, desertification, deforestation and the destruction of natural habitats can also be traced directly to many of those same technologies. This dual legacy of immediate, powerful benefits on the one hand and unexpected deleterious consequences in the long term on the other hand must be recognized by all members of society today. Often, unanticipated consequences in the long run outweigh the short-term benefits.

Nowhere is the need for the understanding of the general populace more urgent than in the young field within biology called genetics. Genetics is the study of inheritance. In less than a century, geneticists have defined the laws governing heredity and located the hereditary blueprint in a type of molecule within chromosomes. By deciphering the chemical code in which these units of inheritance, called genes, are written, scientists have acquired powerful tools for manipulating the messages that dictate our physical makeup. For the first time in history, it is within our power to design life by deliberate human intervention. The possibilities and implications are awesome, but we lack historical, social and cultural guidelines that can lead us through this uncharted territory.

Fragmentation of Knowledge

In the past, people lived within the comfortable confines of a worldview in which everything belonged and fitted together to "make sense." Part myth, part accumulated experience, part insight, part superstition, a worldview is a holistic construct within which all is interconnected. Thus, for example, the birth of a two-headed calf was once interpreted as a portent of an extraordinary event to come or as punishment for something in the past, because nothing occurred in isolation. That view has changed radically. Today the print and electronic media assault us with a vast amount of information presented in snippets to fit an appropriate space or time slot. This proliferation of information and a parallel increase in areas of expertise, each with its own specialized jargon, have shattered the all-encompassing image of the cosmos.

In part, this rupture into disconnected pockets of knowledge is a reflection of the scientific enterprise itself. A unique aspect of science is that its practitioners focus on one aspect of nature, isolating it from all else, measuring everything impinging on and emanating from that fragment. In so doing, scientists gain impressive insights — but only into that separated piece. Scientists, then, learn about nature in bits and pieces, deriving a picture that is both fragmented and unidimensional.

Early in this century, physicists realized that nature is not like an immense jigsaw puzzle whose pieces can be fitted together to provide a comprehensive picture of the whole. Because the pieces behave differently in combination, properties emerge from their interaction that cannot be predicted beforehand. Biologists have been slow to recognize this fact and still believe that if living organisms can be reduced to their most elementary components, a comprehensive picture of life will eventually emerge by their summation.

Once the leisurely activity of gentlemen and aristocrats, science now has enormous national and international consequences. It has grown explosively, especially since World War II, as an endeavor heavily subsidized by national governments for prestige and economic benefit. The rapid increase in the number of scientists (it is said that 90 percent of all scientists who have ever lived are still alive and publishing today) has been accompanied by a corresponding proliferation in disciplines. Thus, a Ph.D. graduate in the early 1960s could simply describe his or her specialty within biology as genetics. Today, one must be much more specific, perhaps referring to oneself as a *Drosophila* (the organism studied) developmental (the specialty) geneticist.

The Scientist As Expert

To the lay public, science is often associated with incomprehensible jargon and a high degree of expertise. Thus, science seems to lie outside the average person's ability to comprehend and evaluate. "Leave it to scientists" is a common sentiment when it comes to determining how new knowledge should be applied.

But who are scientists? What are they like? What drives them? Scientists are seldom accurately portrayed in our popular media. To the public, they are often epitomized by the mad scientists seen in Saturday morning cartoons, or as the noble seekers of truth for human progress. Stripped of passion or romanticized beyond recognition, these images are merely caricatures. Scientists are, above all, human beings with the full range of human foibles and traits.

Given that scientists are human, can't we assume that most scientific endeavors serve the best interests of humankind? The answer is no, for a number of reasons. The most important reason is that the two major users of scientific knowledge today are the military and private industry. Thus, destructive *power* and *profit* are the main engines driving the exploitation of new knowledge. The long-term environmental or social consequences of new scientific applications seldom carry much weight in the face of these priorities. Scientists who are funded by or seek support from the military or private industry have too strong a vested interest in maintaining that support to be objective about their work.

There is another reason that scientists will not always act in the public interest. Within the hierarchy of scientists, maintaining or advancing one's position depends on continual publication and the maintenance of grants. To keep publishing papers and getting grants, scientists must remain glued to the lab bench, where attention is focused on the questions at hand. Under these circumstances, it is difficult to see beyond the barrel of the microscope. Thus, the broader social implications of new discoveries generally lie outside the restricted field of vision of active scientists. Those scientists who do step back to consider the broader ramifications of their research too often lose credibility for ceasing research. Thus, a lay public that is subsidizing the scientific enterprise through research grants, support facilities and tax breaks and that is directly affected by the application of scientific knowledge must be responsible for determining the direction of science and its application.

Controlling the Juggernaut

History informs us that while the benefits of new technologies are immediate and obvious, there are always costs, which are usually hidden and unpredictable a priori. Around the world, governments are urging the scientific community to exploit their discoveries in some practical way. But there is considerable hazard in this headlong rush. While we are regularly assailed by claims of scientific "breakthroughs," most of the information accumulated by scientists represents an incremental increase in our understanding of nature, and new ideas are tentative.

Those who graduated as licensed scientists in the 1960s were at the cutting edge of genetic research. The molecular nature of genes was very well known, and there were elegant models showing chromosome structure and how genetic activity was controlled. Today's students smile at the naiveté of the ideas and