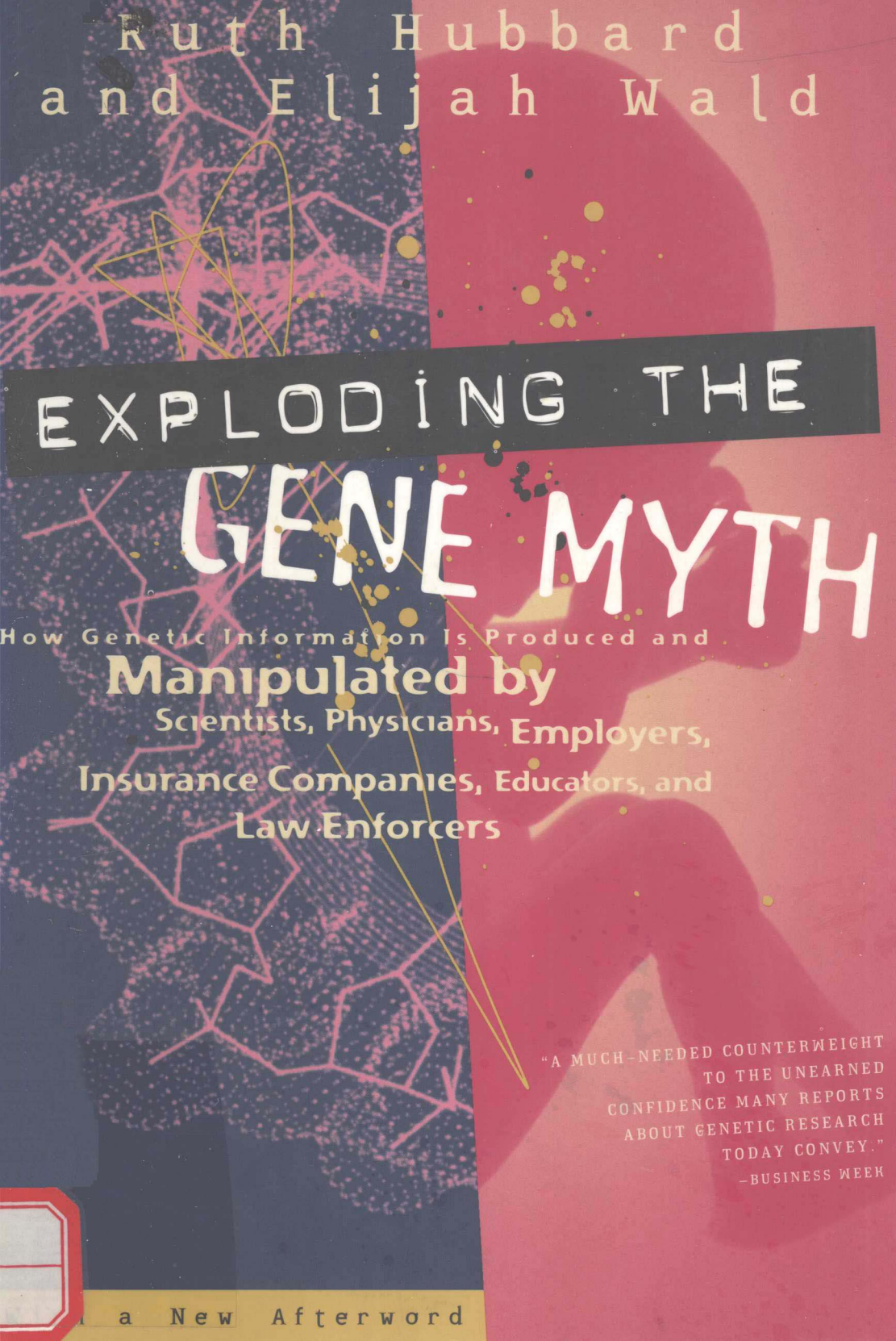
Ruth Hubbard
and Elijah Wald
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–BUSINESS WEEK
a New Afterword

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With a New Afterword

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To Hella and Richard

who contributed much more than their genes

"WE USED TO THINK OUR FATE
WAS IN THE STARS.
NOW WE KNOW, IN LARGE MEASURE,
OUR FATE IS IN OUR GENES."

—JAMES WATSON, *Time,* March 20, 1989

"WE CANNOT THINK OF ANY SIGNIFICANT
HUMAN SOCIAL BEHAVIOR THAT IS
BUILT INTO OUR GENES IN SUCH A WAY
THAT IT CANNOT BE SHAPED
BY SOCIAL CONDITIONS."

—*Not in Our Genes: Biology, Ideology, and Human Nature,*
by R. C. LEWONTIN, STEVEN ROSE, AND LEON J. KAMIN

Preface: Why This Book

A revolution is happening in the biosciences. Newspapers and magazines constantly report discoveries of genes for this or that disease, disability, or ability and many people believe that new biotechnologies will transform our lives more profoundly than transistors and computers have done. Yet genetics remains a specialized subject, and few people are equipped to evaluate how the new wonders will affect them. Words such as "genes" and "DNA" fly about. But what are genes and DNA, and how do they function?

We need to have a realistic sense of the positive contributions genetics and biotechnology can make, and of the risks inherent in the science, its applications, and its commercialization. We also need to understand that biotechnology can change not only how we live but how we think of ourselves and other animals. Are living organisms machines, so that it is safe to replace a gear here and a cog there, or are we too complex for anyone to foresee the effects of genetic tinkering?

This is a critical time in the development of genetics and biotechnology. Legislatures, courts, government agencies, and commissions are breaking new ground and making decisions about questions such as whether our genes can be patented or stored in data banks, how to prevent new forms of discrimination based on genetic information, and how to keep genetic information private.

It is crucial that we, as citizens, not leave this process in the hands of "experts." Like other people, scientists are interested in seeing their projects flourish, and their enthusiasm can blind them to the possible negative effects of their work. Since we will all have to live with those effects, we must become sufficiently informed to be able to decide to what extent

genetics and biotechnology can improve our lives. We cannot just sit by as passive worshipers or victims.

This book is intended to provide an overview of what is occurring in modern genetics and to make it easier to understand and evaluate current applications of genetic research. In this rapidly changing field, in which scientific papers often are outdated even before they appear in print, it would be foolish for me to pretend to cover the most recent findings. Rather, I want to provide something like a basic survival handbook, a compass, and a few guideposts. For readers not trained in biology, I will try to present enough science to let you form your own opinions about the reports you read in the press. In addition, I want to give some historical insight into the destructive consequences of past overuses and misuses of genetics by scientists, physicians, and politicians, in this country and in Europe. At the end of the book, I have included a glossary of scientific terms and a list of books and organizations which can provide further information on the various subjects I discuss.

Although two of us have worked on this book, it is written in the first person. This is because I, Ruth Hubbard, am a biologist and take responsibility for the scientific content and for much of the interpretation we present. My coauthor, Elijah Wald, is a writer and a musician who believes, as I do, that anything worth saying can be said clearly enough so that people without special training can understand it.

I could not have written this book without the help of numerous friends and colleagues over many years. First and foremost I must mention my fellow members on the Board of Directors and the Human Genetics Committee of the Council for Responsible Genetics: Philip Bereano, Paul Billings, Liebe Cavalieri, Terri Goldberg, Colin Gracey, Mary Sue Henifin, Jonathan King, Sheldon Krimsky, Richard Lewontin, Abby Lippman, Karen Messing, Claire Nader, Stuart Newman, Judy Norsigian, Barbara Rosenberg, Marsha Saxton, Susan Wright, and Nachama Wilker, executive director of the Council for Responsible Genetics. Our collective work and discussions have guided and clarified my thinking about all the issues I discuss in this book. I have also profited from discussions with Charles Baron, Alice Daniel, John Roberts, Melvin Schorin, and Ernest Winsor, my fellow members of the Medical-Legal Committee of the Civil Liberties Union of Massachusetts. Over the years, I have profited from ongoing conversations with Rita Arditti, Adrienne Asch, Jon Beckwith, Joan Bertin, Lynda Birke, Robin Blatt, Carolyn Cohen, Richard Cone, Mike Fortun, Robin Gillespie, Stephen Jay Gould, Evelynn Hammonds, Donna Haraway, Sarah Jansen, Evelyn

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Contents

ONE

Of Genes and People

The Role of Genetics in Our Lives

We meet with genetics all the time, though we don't always recognize it. When we go to a doctor, we are first asked about our "family history," the diseases our parents or siblings have had. Only later, after the doctor has begun to form a theory about our problems, are we likely to be asked questions about our lives: where we live, what we eat, and the way we live in general. Despite the wide range of occupational health hazards, we are rarely asked about our jobs unless we have specific work-related complaints.

This "family history" is an attempt to come up with a genetic framework into which our problems can be fitted. The doctor uses this information about our relatives' health conditions as an aid in predicting what we may expect in our own lives. Such histories can include only what we happen to know about our family and therefore give only a rough picture. Modern genetic research tries to go beyond that, by looking at manifestations of inherited traits and eventually at genes themselves.

Such histories, whether based on family anecdotes or medical tests, are also looked at when we want to buy health or life insurance. They may determine whether we receive coverage and what premiums we will have to pay. More and more, they are required by prospective employers, and can affect whether or not we get a job.

A generation ago, people thought mostly about their economic and family situations when they considered whether they should have children. Today, they are often expected to undergo medical tests at every stage of the process, from premarital or preconceptive blood tests to amniocentesis during pregnancy. All this information is supposed to be useful. Doctors hope that it will give them a better understanding of our

health problems, and help them prevent or cure these problems. Insurers and employers hope that it will let them predict their future liabilities. We hope that it will help us to remain healthy and have healthy children.

The problem with linking all our health conditions to genes is that it makes us focus on what is happening inside us and draws our attention away from other factors that we should be considering. The genetic epidemiologist, Abby Lippman, has called this process *geneticization*. She writes:

> Geneticization refers to an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health. Through this process, human biology is incorrectly equated with human genetics, implying that the latter acts alone to make us each the organism she or he is.[1]

Currently a new industry is being built on hopes of better living through genetics. Molecular biologists—the scientists who study the structure and function of genes and DNA—are acting as directors, consultants, and shareholders in biotechnology companies that seek to capitalize on every aspect of genetic research. Firms with names like Biogen, Genentech, Genzyme, Repligen, NeoRx, and ImClone are producing everything from predictive tests to drugs, hormones, and modified genes.

Biotechnology firms have been expensive to set up, and have lured investors who expect rich profits in the near future. This means not only that they have to put products on the market as soon as possible but they must create a market for those products. They are producing a host of tests and medications, and making glowing promises about the benefits to be derived from the use of these products. The evidence to support such promises is often slight or even nonexistent, but since most of the medical and scientific experts in the field are also connected with the industry they are inclined to be optimistic.

While the benefits of the new products are often illusory, disadvantages are appearing which are all too real. People have been refused employment or insurance on the basis of genetic tests whose results have no significance. Women have been needlessly frightened about the outcome of their pregnancies. Treatments with potentially harmful effects have been started without sufficient testing.

A more basic problem is that genetic tests and modifications encourage us to look upon ourselves as a collection of tiny discrete parts, rather than as whole human beings. Since we ourselves cannot do anything to

change these parts, we are forced more and more frequently to entrust ourselves to specialists who supposedly can. Yet it often makes much more sense to deal with the whole human being, rather than to tinker with the parts. This can involve things that are much more in our control, such as changing where or with whom we live, what and how much we eat, or other aspects of our lives.

The process of reducing objects or organisms to their smallest parts rather than looking at them as a whole is called *reductionism,* and it is not confined to genetics. In the last century or so, reductionism has become a major force in science. From Pasteur's bacteria to the physicist's atoms, we have grown used to the idea that the smallest things can have the most overwhelming effects. In biology, reductionism fosters the belief that the behavior of an organism or a tissue can best be explained by studying its cells, molecules, and atoms and describing their constitution and function as accurately as possible. However, reductionists often lose sight of the forest in their zeal to examine the ridges on the twigs of the trees.

In the biological sciences, the status once enjoyed by naturalists, who observe how animals live and what they do, has shifted to molecular biologists, who study DNA molecules and segments of these molecules which they call genes. Most modern biologists believe that work at the molecular level will yield a more profound understanding of nature than they could get from the study of cells, organs, or entire organisms. The fact that experiments with animals are more difficult to control or duplicate than experiments in test tubes has made it easy to dismiss the former as fuzzy science. Molecular biology has therefore become the most prestigious of the biological disciplines.

In the last few years, molecular biologists under the auspices of the National Institutes of Health and the Department of Energy have mounted a project that has been compared to the U.S. space program for its scope and expense (a projected three billion dollars in fifteen years). Called the Human Genome Project, it is an attempt to map and sequence all the DNA of a human "prototype." This is reductionism at its most extreme, as genome scientists will be constructing a hypothetical sequence of submicroscopic pieces of DNA molecules, and will then declare that sequence to be the essence of humanity.

Harvard molecular biologist and Nobel Laureate, Walter Gilbert, has referred to the human genome as the "Holy Grail" of genetics.[2] Such imagery, intended to elicit a religious awe for the wonders of science, has become common among genome scientists and is carried over into most media reports on the project. For instance, a "NOVA" television program on the human genome referred to it as the "Book of Life." James Watson, author of *The Double Helix* and the first director of the National

Center for Human Genome Research, avoids explicit religious metaphors, but says his objective is "the understanding of human beings" and of life itself.[3]

Being human, however, is not simply a matter of having a certain DNA sequence. Molecular biologists are no more qualified than the fabled guru on the mountaintop when it comes to telling us the meaning of life. They can give some answers for some aspects of the question, but their answers are useful only in specific contexts.

GENES FOR DEAFNESS, GENES FOR BEING RAPED

While most people have never heard of the Genome Project, no one can miss the flood of gene stories in the popular press. For instance, one day's "Medical Notebook" section in the *Boston Globe* contained these four headlines: "Genetic link hinted in smoking cancers." "Schizophrenia gene remains elusive." "A gene that causes pure deafness found." "Do the depressed bring on problems?"[4]

Once, this emphasis on genes would have seemed surprising, but in the last few years such stories have become commonplace. We all see the articles, but we do not always bother to read them. For most of us, genetics remains something complicated, scientific, and a bit boring. And yet, the subjects being discussed are often very close to home. They include alcoholism, cancer, learning problems, mental illness, sex differences, and such basic processes as aging.

The four *Globe* stories are typical of most current reporting on genetics, both in the mass media and in scientific journals. They contain a mix of interesting facts, unsupported conjectures, and wild exaggerations of the importance of genes in our lives. A striking thing about much of this writing is its vagueness. In the first headline, for example, a "link" to smoking cancers is "hinted." The story itself says "a report released this week . . . *suggests* certain individuals *may* carry a gene that makes them especially vulnerable to smoking-related cancers" (italics mine). It then tells us that the researcher estimates that 52 percent of the population "may" have such a gene, "if it exists." In other words, it is possible that slightly more than half of us are particularly susceptible to lung cancer if we smoke. The remaining 48 percent of us may perhaps be less susceptible, although smokers are still at significantly greater risk than nonsmokers.

Even if such a "cancer gene" were isolated, that would not change the fact that smoking is harmful, nor would it help people to quit smoking

or doctors to treat cancer. This information would therefore not be useful to most newspaper readers, even if the article contained valid scientific conclusions. So why is it published? One reason is that both genes and the dangers of smoking currently are of interest to a lot of people. Another is that such information could be extremely useful to cigarette companies. As people with lung cancer are beginning to sue these companies, the companies would love to be able to blame the cancers on these people's genetic "susceptibilities." If the people bringing suit turned out to be in a special high-risk group, the companies could disclaim responsibility. If that high-risk group includes over half the population, that is not the companies' problem.

Many new genetic breakthroughs are like this. They do not make people healthier; they merely blame genes for conditions that have traditionally been thought to have societal, environmental, or psychological causes. News reports about such studies fuel the widely held perception that our health problems originate inside us and draw attention away from outside factors that need to be addressed. Scientists did not create this perception, but they contribute to it when their interest in genes keeps them from emphasizing, or even admitting, that there are other ways to explain our health problems.

Witness the next piece in the "Medical Notebook." It begins, "A series of attempts to confirm the existence of a gene for schizophrenia have failed, three years after the announcement of an apparent gene link caused a stir among mental health researchers." If a link cannot be confirmed after repeated attempts, that would seem to suggest that the condition is not genetic. However, the column quotes a psychologist named Irving Gottesman as saying that "studies continue to indicate that a gene or genes creates 'risk-enhancing factors' for schizophrenia."

The studies he refers to show that people who have schizophrenic siblings are somewhat more likely to be schizophrenic than people who don't. Since many psychiatrists think that schizophrenia is caused by family problems, this result is not at all surprising. To call it "evidence" of genetic factors is at the very least misleading.

Like the smoking study, this is a story built on air. Such articles suggest that genes are involved in all sorts of conditions and behaviors, but all they really tell us is that a lot of money is being spent on genetic research. The grandiose nature of the claims disguises the fact that the research is not particularly newsworthy.

The next *Globe* story gives an example of the more responsible kind of genetic research. Scientists have identified "a gene that causes pure deafness," the first such gene to be found. All the people with this par-

ticular form of deafness are members of one extended family in Costa Rica. The fact that this gene has been isolated may help scientists to understand other kinds of deafness as well, though that remains to be seen.

This sort of basic research increases our body of knowledge and can be useful. However, it is not the sort of discovery that normally gets into the daily papers. It is in the *Globe* because it is a gene story and, unpretentious as it is, adds solid facts to the featherweight claims in the other stories.

The myth of the all-powerful gene is based on flawed science that discounts the environmental context in which we and our genes exist. It has many dangers, as it can lead to genetic discrimination and hazardous medical manipulations. The last *Globe* piece is an extreme example of the dangerous and unwarranted conclusions that are sometimes drawn from genetic research. It reports a survey by Lincoln Eaves, a behavioral geneticist, of research by various investigators on twelve hundred pairs of female twins whom the investigators considered to be prone to depression. Eaves said he found evidence of genetic causes for this depression, though the evidence is not provided in the article.

Eaves also administered a questionnaire "asking whether the volunteers had suffered traumatic events, such as rape, assault, being fired from a job, and so forth." He found that the women who were chronically depressed had suffered more traumatic events than those who weren't.

Now, if he were not assuming that their depression was genetic, he might suspect that they were depressed because of the bad things that had happened to them. However, his interest is genetics. So, the article continues, Eaves "suggested that [the women's] depressive outlook and manner may have made such random troubles more likely to happen."

What kind of reasoning is that? The women had been raped, assaulted, or fired from their jobs, and they were depressed. The more traumatic events they had experienced, the more chronic the depression. This suggests that depression brings on problems? If Dr. Eaves had found that football players frequently get fractures, would he have suggested that brittle bones make people play football? It might have been worth looking for a genetic link if he had found that the depression was not related to any life experience. But once he found a clear correlation between traumatic events and depression, why look for a genetic explanation?

Ridiculous as this research may be, the press reports it with a straight face. At present, genes are newsworthy and virtually any theorizing about them is taken seriously. This is not the fault of the media. Science, government, and business are all hailing genetics and biotechnology as the wave of the future.