THE PERFECT BABY

PARENTHOOD IN THE NEW WORLD OF CLONING AND GENETICS

SECOND EDITION

GLENN McGEE

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Second edition

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ROWMAN & LITTLEFIELD PUBLISHERS, INC.
Lanham • Boulder • New York • Oxford

ROWMAN & LITTLEFIELD PUBLISHERS, INC.

Published in the United States of America.
by Rowman & Littlefield Publishers, Inc.
4720 Boston Way, Lanham, Maryland 20706
http://www.rowmanlittlefield.com

12 Hid's Copse Road
Cumnor Hill, Oxford OX2 9JJ, England

British Library Cataloguing in Publication Information Available

Library of Congress Cataloging-in-Publication Data

McGee, Glenn, 1967–
The perfect baby : parenthood in the new world of cloning and genetics / Glenn McGee.—2nd ed.
p. cm.
First edition has subtitle: A pragmatic approach to genetics.
Includes bibliographical references and index.
ISBN 0-8476-9758-4 (cloth : alk. paper)—ISBN 0-8476-9759-2 (pbk. : alk. paper)
1. Eugenics. 2. Genetic Engineering. I. Title

HQ751.M358 2000
613.9'4—dc21 00-021041

∞™ The paper used in this publication meets the minimum requirements of American National Standard for Information Sciences—Permanence of Paper for Printed Library Materials, ANSI/NISO Z.39.48-1992.

THE PERFECT BABY

PREFACE
TO THE SECOND EDITION

About midnight one Sunday morning in February 1997, a week after the first edition of *The Perfect Baby* was released, I was awakened by a telephone call from an Associated Press writer. She excitedly told me about a sheep in a small village in Scotland, named Dolly after country music singer Dolly Parton. She said the sheep had been *cloned*, the magical deed performed by a quiet scientist named Ian Wilmut who had adopted his own children and had no intention of cloning people. The reporter had seen an announcement of *The Perfect Baby* in the prior day's *New York Times* and wondered what a "bioethicist" was and what such a person thought about making cloned sheep or cloned people. "First tell me—are you sure about this sheep?" I quizzed. It seemed impossible news.

I wiped the sleep from my face and contemplated the implications of a cloned mammal. I made some comments to the reporter about my research on how genetic engineering is changing the meaning of parenthood, then went to sleep. The next morning my comments appeared in every newspaper in the nation. Another reporter called, and another, and another. For thirty-eight hours I shuttled from one television studio to another to make comments to millions of stunned people, through radios, televisions, web browsers, and newspapers. Giving "sound bites" on television about cloning was an odd experience for a philosopher, but I found that I was able to provoke interesting debates and to get people interested in learning more about this new science. After about a hundred interviews I lost count of how many times I had talked to Dan Rather, Ted Koppel, Peter Jennings, the *London Times*, or any of dozens of producers from everywhere. I even did several interviews about what it was like to suddenly have to do a hundred interviews, and PBS talk show host Charlie Rose suggested to me that if I talked about cloning one more time I would be offered a Nike shoe deal.

I finally stopped talking, the shoe deal didn't come through, and many of my friends in philosophy, along with "experts" ranging from a mouse geneticist to a retired physicist, joined what has become a robust conversation about reproductive genetics and cloning. Today there are literally dozens of books and thousands of articles about cloning and genetics. *The Perfect Baby* is an attempt to focus on the effect these technologies have on what it means to be a child, and what it means to be a parent, but it is also an exploration of the relationship between philosophy, social science, and public life. This second edition you have before you explores some of the many technologies and possibilities that have emerged since the original edition was released in 1997. Changes in genetics and reproduction have happened at such a rapid pace that even computer technology seems stable by comparison, and no attempt is made to address every recipe in the cookbook of new reproductive technology. This is an introduction and an invitation to explore the odd, surprising, and important world of human genetics and reproduction.

PREFACE
TO THE FIRST EDITION

We say we have found the perfect wine for a particular dish. The perfect bride is known so only by her groom, and celebrated as such only for a week. The perfect day brings together elements of atmosphere, emotion, and planning; we know it when we experience it, and we plan it with breathless anticipation and the recognition that rain means doom. What is the *perfect baby*? Parents tell us that whichever baby they bring into the world is perfect. And we smile and acknowledge that the making (and having) of a baby is indeed an epiphany unlike any other we are likely to experience. We celebrate as a perfection that time in which some strange constellation of luck, planning, and biology sweeps over us like a (perfect?) wave. Perfect babies can have big ears and wail like banshees; they may be blind or have fewer fingers than other babies.

But the perfect wine is also an advertising campaign, a way of promising that some brand of wine is better than the others. And the perfect bride is sketched out in gruesome detail in the wedding magazines, an icon to which virtually no one lives up. The perfect day is a picture that sells beer and cigarettes. And the perfect baby is becoming a subtle commercialization of the same ideal traits that shaped eugenics at the turn of the twentieth century. Biotechnology companies rush ahead full speed to develop genetic tests that will tell families very little but allow very grave choices. How are families to decide whether or not to abort a child who might sixty years later develop Alzheimer's disease, who might forty-five years later go mad from Huntington's chorea, who might twenty years later die of cystic fibrosis or breast cancer, or who might manifest

Down's syndrome in a couple of years? Genetic counselors are so acutely aware of the historical tragedies associated with eugenics that they have adopted strange and hollow neutrality. Legally, today it is every woman for herself. Morally, no institution of society has acknowledged our collective responsibility to think about and develop the wisdom and methods for new decisions about genetic research, genetic tests, and gene therapies.

This book is an attempt to think and write about genetic interventions. Rather than reviewing the attacks on or defenses of genetic testing that have been written by prominent philosophers and theologians, I deal here with the texts actually read by scientists and parents. And I discuss the ideas that are in play in our actual discussion of parenthood and babies, about ideas like identity, perfection, enhancement, and illness. The history of genetics in the past two hundred years could in some ways be characterized as a race toward the mapping and utilization of all the genetic information in our bodies. While the technologies produced by the effort to find and identify all of our genes are new, our cultural and social goals for the use of those technologies are rooted in the history of human inquiry into heredity. In science and in families, there is a long history of interest in improving the quality of offspring. This history is, in some ways, infamous: societies have sterilized hundreds of thousands of people in the interest of eugenics. But decisions about the purposes and context of reproduction are unavoidable and are always made in a social context. People talk about perfect babies, whether or not they use a blueprint to define them.

As the new reproductive and gene therapy technologies make diagnosis and cure of genetic anomalies possible, long-standing questions about social control of reproduction will have to be confronted. Hopes and fears concerning human genetic exploration have been catalyzed by the Human Genome Project and the cloning of Dolly the sheep. Many believe that genetic engineering will radically alter human experience in wonderful, dangerous, or disastrous ways. In this book I discuss some intelligent goals for genetics within its social and political context.

ACKNOWLEDGMENTS

In addition to the legion of people and institutions at the University of Pennsylvania and elsewhere whom I acknowledged in the first edition of *The Perfect Baby*, several deserve thanks (but no blame) for various aspects of the second edition. In particular, I thank Maryhelen D'Ottavi, Charles Bosk, Norman Daniels, Peter Ubel, Matthew Weinberg, Ann Cook, Eric Juengst, Erik Parens, John Robertson, Herman Saatkamp, Michele Dewey, John McDermott, Jackie Kegley, Laurence McCullough, Andrea Gurmankin, Arthur Caplan, and Ronald Dworkin.

I am grateful to the Foreign Office of the British Government and to the British Council for an Atlantic Fellowship in Public Policy, which both enriched my opportunity to research emerging technologies and gave me exposure to international political dimensions of genetics. I benefited from time spent at Kings College London and from the opportunity to present parts of this work in lectureships, talks, and grand rounds at dozens of universities and hospitals to helpful students, faculty, clergy, scientists, and clinicians.

I am also thankful to my extraordinary editor, Maureen MacGrogan of Rowman & Littlefield, to Scott Wolfman, and to both my father, Daniel McGee, for allowing me to amplify our argument that infertility is not a disease, and my friend David Magnus, for allowing me to draw on our work on the history of eugenics.

Monica and Ethan McGee make it fun to be around in the first place and put up with my patent eccentricities while I write.

London, England

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the landscape of genetic technology

Catherine and Clay Johanson don't want to answer the phone. It rings again. He's in the backyard, where he can pretend not to hear anything over his weed trimmer. She attends to their son, Paul. On the other end of the line, Claire Redman, a genetic counselor at the University of Washington in Seattle, can anticipate the conversation. She doesn't need to tell the Johansons about cystic fibrosis. The difficult hereditary disease has already visited its agonies on the family. Their son, now three, celebrated his second birthday in a CF clinic at Emory University in Atlanta, where pulmonologists, dieticians, pediatricians, and a team of special nurses were working around the clock to keep him from drowning in the thick mucus that clogs his lungs. This morning Paul is back at home, and Catherine fills his belly with sweet potatoes and apple juice. She is thirteen weeks' pregnant. Answering the telephone means being told whether or not the fetus she is carrying will also have the disease. It is a difficult choice they are about to make. Their friends hesitate to talk about it. Catherine and Clay have spent a couple of tough nights over coffee with Father McBry of their Bellevue, Washington, church. Today, the wait ends.

In Newton, Massachusetts, Rhoda and Michael Salvano are also waiting for a phone call. Michael doesn't have much more time. He is awaited at work by his team of young, ambitious architects, each of whom needs his approval to move forward on some chunk of the sixty-three-story building they are to conceive and build in São Paulo, Brazil. In the five years they have been married, Rhoda and Michael have made all the normal attempts to start a family. They made love daily for months. They timed their activities, he wore boxer shorts, he took the right vitamins, he drank lots of water. If Tia Marie said that Tuesdays were good for conceiving, Mike and Rhoda took the day off. In March they gave up and made initial forays into the world of adoption, but then neighbors recommended an assisted reproductive technique called in vitro fertilization (IVF). Their reproductive endocrinologist, Dr. Charles Madrigliani, assured them that their problems are common and that assisted reproduction might indeed save the day. However, he told a stone-faced Michael that the motility of his sperm was so low as to present a real threat of failure. IVF is already expensive, he explained, and Mike's insurance would not pay for infertility treatments or assisted reproduction. And in Rhoda and Mike's case, the only option that would allow Mike's sperm to fertilize one of Rhoda's eggs is Intracytoplasmic Sperm Injection (ICSI). Through this procedure, an infinitesimally small glass needle could be used to "help" one of Mike's weak and struggling sperm into an egg harvested from Rhoda. Before the couple could get excited about this last hope to have genetic children, Madrigliani pointed out that the whole package, ICSI and IVF, could cost upwards of half of Mike's annual salary for *each attempt* and that more than half of the attempts to use these procedures to implant a fetus fail. Moreover, many couples continue to pursue adoption during the waiting period, which will typically cost tens of thousands of dollars as well.

Mike and Rhoda decided against ICSI. The cost was too great and the results still uncertain. Mike wondered if this new procedure would result in a child born of sperm that nature had not certified. He dreamed of a son who was lethargic, and it hurt. Rhoda tenderly approached the question of how important it really was that the child be their genetic offspring. She was adopted and had always wanted to have a child—to have someone—who looked a little or acted a little bit like her. But she too wanted to make the right choice. And when one evening she caught a television special, she knew they had found the answer. The answer, she told Mike, was fertilityoptions.com. And so, today, after months of hard work of one kind or another, Mike and Rhoda waited for a conference call with the California sperm bank, which promises to let them pick their sperm donor from web pages filled with information about each candidate. For less than the cost of ICSI, Mike and Rhoda hope to give their child both some of their genes (from Rhoda) and the best possible genetic start. They will "camera match" the sperm donor to a picture of Mike, so that no one will ever know (not even the child) that IVF or a donor was involved.

In Philadelphia, scientists at the University of Pennsylvania plug away. Behind the ivy-covered walls of one of biology's best-known fortresses, the Wistar Institute, a quiet battle is being waged against dozens of diseases. These are the white-coated soldiers of the Institute for Human Gene Therapy, home of the most important part of the world's attempt to use genetic interventions to cure diseases. Here, Dr. Jim Wilson and perhaps a hundred other geneticists go through technical procedures that have become almost a mantra. It looks pretty mundane to the casual visitor. But for Wilson, scarcely forty, it is the final frontier of gene therapy. The goal is to develop what geneticists call "vectors."

Vectors are the vehicles that will transmit genetic information into the cells of patients. They are mostly modified adenoviruses—the flu reconstructed to infect a patient, producing more and more cells that could overwhelm a disease or mitigate its effects. When you get Wilson to talk about the possibility that they will work, he beams. The right vector could help give Catherine and Clay Johanson's son a chance at a normal life. Paul could use an inhaler to suck in the viral vector, catch the modified flu, and slowly receive genetic information programmed into the vector, which could change the infected portions of his lung so that they no longer secrete the thick mucus that requires his parents to pound his back and that will otherwise, eventually, kill him. But the search for this "right" vector is more than a tough battle. One of the dozens of lab assistants wears a button that puts it best: "Does anything but shit ever happen?" Present inhalers for CF patients have failed again and again. At normal doses, the modified virus seems to fail in its task of transmitting enough good genetic information to make a difference. To get a high enough dose of the vector, inhalers have to be ramped up so high that they pour a cloud of the flu virus into the already clogged lungs of the patient. This is what occupies Wilson and his colleagues this morning, as they too wait for a telephone call from the Food and Drug Administration about whether it is time to move to clinical trials of the next vector for the next disease.

It may be a new world in Washington, Massachusetts, and Pennsylvania, but thinking about human heredity is nearly as old as thinking itself. And the tough choices of the new genetic era are really not much tougher than the choices faced by parents every day around the world. Everyone must deal with the issues of parenthood, even those with no children and those with foster or surrogate parents. In schools and in churches there is much worry about the meaning and scope of parenthood. In the halls of power and around the dinner table people worry about the personal and political meanings of parenthood. Hillary Clinton reminds Americans that it takes a village to raise a child, and Marian Wright Edelman points out that even a village can abuse them.

Nor are we just now learning what families are all about. We develop our ideas of the family from children's books and from *Mr. Roger's Neighborhood* and as adults come to question the normalization of different kinds of families. Is a good father like my father or not? How much of my own experiences do I want to pass along? We also ponder distinctions between natural and learned identity. Why do we look, and act, like our parents and ancestors—and in what sense are we ever free of our heritage? There are stories to guide us here as well, for our culture is filled with them. And we have more rigid characterizations of the good family. Our courts issue decisions about who counts as a mom or a dad and about what kinds of responsibilities come with those roles. If you don't vaccinate your children, you may be compelled to do so. If you conduct yourself inappropriately with your children, society will take over the role of parent. Businesses sell us ways of improving our families, and churches offer us models of virtuous parenting and even virtuous childhood. Eastern and Western cultures have developed extensive and intricate ways of thinking and talking about heredity and folkways that acknowledge the importance of biological parenthood to culture.

We have been thinking about the biological dimensions of what has come to be known as "heredity" for a long time. Our efforts to control it systematically began with the cultivation of crops at least ten thousand years ago. Human domestication of animals involved both the elimination of weaker cattle and the use of selective breeding. It was used on sheep, goats, oxen, camels, and other animals on the African continent. Assyrian records indicate that as early as 5000 B.C. the use of artificial fertilization was common in the cultivation of date palms. Gradually, the manipulation of animals and plants became an important part of economic growth. The economy of Troy was based on horse breeding.

Study of *human* heredity has historically been linked to social and medical concerns. Diverse traditions maintained that "blood" is of importance in illness and in social and familial affairs. The Talmud makes mention of the inheritability of hemophilia. Members of the tribe of Levi exclusively inherited the Jewish priesthood. Hindu castes are based on the assumption that "both desirable and undesirable traits are passed from generation to generation."[1] Several Native American tribes hold that the maintenance of tribal integrity hinges on the restriction of intertribal marriages.

Western theories of human heredity were first recorded in the Greek doctrine, which asserted that sperm carries hereditary information and "vital heat" from father to offspring. The sperm thus directs the form of the baby. Aristotle disputed the notion that females had the vital heat necessary to contribute to the form of the offspring and also held that traits acquired by parents during their lifetime might be passed to offspring. The theory that experiences acquired during life could be passed to offspring helped Greeks account for strange differences in appearance among parents and children. For example, Aristotle postulated that a child whose eye color differed from both parents might have acquired the trait from parental experiences.

Despite all these efforts to predict and control the reproduction of plants, animals, and people, the real explosion in the study of the biological family dates only to the past two hundred years. Right alongside has also advanced the practical power to effect changes in families. We have come to think of ourselves as having control over much of relatedness and the family. We talk about a concept called social and biological *identity* of children, a notion forged through years of advancing disciplinary study of inheritance, relation, and what counts as a good baby.

The explosion in the modern, and eventually molecular, investigation of heredity occurred in the early 1800s, when research focused primarily on the problems of inheritance in plants important to a large commercial breeding industry: How do the offspring of a flower keep the structures and appearance of their predecessors? To answer such questions, scientists sought to uncover laws of biology, applicable to all organisms, that would explain both inheritance and development.

The introduction of the microscope in the 1600s had led to the discovery by Robert Hooke that plants and animals were made up of *cells*. Cells seemed to provide a kind of matrix for biological life composed of independent nodules of activity bustling within every living organism. It remained impossible, though, until the late nineteenth and twentieth centuries, to explain the role of heredity in cellular functioning. How and why do cells divide, reproducing the information crucial to a stable identity in any organism? What kind of cell can replicate to make a whole organism, and what sort can only divide to make more of the same kind of cell?

Gregor Mendel's experiments with garden peas, which began in 1856 and were published in 1866, began a discipline called *genetics*, which concerned itself with the relationship between traits in the parent and traits in the offspring. Mendel fertilized hybrid peas and observed differences effected by mixing and matching. He identified certain traits, such as height and color. Mendel noticed that a "recessive" trait would vanish from the second generation of plant offspring, then reappear in the third generation in a ratio of one to four. He postulated that a biological explanation for observable differences in offspring must exist and called that foundation the "formative element."

In 1869, Johann Friedrich Miescher discovered what he called "nuclein" (which we today think of as DNA) while working on white blood cells. Nuclein could be distilled from the nuclei, a gray precipitate that seemed essential to the nucleus of cells. E. Zacharia and Walther Flemming began to make connections between heredity and this material; Flemming observed that the material is also present in fused sperm and egg cells. We owe the discovery of chromosomes, the structures that were formed of this nuclein, to August Weismann and other workers in this area in the 1880s, but also to the German dye industry whose clothing dyes were used as biological stains (the name chromosome literally means "colored body"). By the 1890s, nuclein, or "chromatin" (finally "chromosomes"), was thought to contain the basic instructions for hereditary traits.

While Mendel, Miescher, Weismann, and those who evaluated and contributed to their work forged ahead in the laboratory, zoological investigation into "formative elements" in heredity was being catalyzed by Charles Darwin. In his *Origin of Species*, Darwin crafted an elaborate explanation of the role that heredity plays in the production of whole organisms. He constructed an account of the relationship between cellular biology and the purposive activity of animals.

Darwin formulated the principle of "natural selection." He observed that most animals "produce more progeny than can reasonably survive."[2] Differences among offspring make them more or less suited to survival in a particular environment. The principle of natural selection dictates that organisms with traits more favorably suited to the environment will reproduce more frequently and more of the offspring will survive—preserving traits that are conducive to survival in a particular environment.[3] Over time, substantial changes may be required for survival. Aggregations of favorable traits may produce a distinctly new kind or *species* of creature.

Natural selection theory was an important step toward the modern account that linked animal and human behaviors to biological heredity. Darwin attempted to bridge the huge gap between theoretical biology on the one side and botany, zoology, and human social theory on the other. But Darwin was "pointing along a route which he could not trace. For example, in the absence of a theory of the gene, Darwin could not explain the maintenance of inherited variation that was essential for [his] theory to work."[4]

Darwin's work encouraged those whose research concerned social and political life. He also catalyzed the application of Mendelian and Miescherian genetics to human heredity. Though it has not often been recognized, one immediate implication of Darwin's interdisciplinary research on genetics was a move by many biologists toward *eugenics*. This concept was named at the turn of the twentieth century by Darwin's cousin Francis Galton, who argued for "the science of improving human stock" in his work *Hereditary Genius*. Galton envisioned cultural, societal, and familial planning that would move us toward a "better race of men," produced by a series of "judicious marriages over time."[5]

Galton synthesized the word *eugenics* from the Greek *eugenes* (wellborn).[6] The history of the twentieth-century eugenics movement he started has been widely chronicled and is associated with what were eventually thought of as nefarious political aims. However, policies and arguments that could be described as eugenic both predate and antedate that movement. With every significant advance in reproductive genetic technology, fears of eugenics are revived in social and political institutions around the world. Eugenics is both rooted in the history of biology and tied to contemporary debates and is thus always complicated by its past and future.

That eugenics is a difficult concept to define is in part a result of its disparate origins and uses. Long before Galton described systematic eugenics, cultures had devised strategies for the regulation of reproductive relationships. Society has always exercised a measure of control over reproduction: in sexual recombination, it takes two to reproduce, and those two choose each other under the influence of family, economic, political, and other community values.