

BIOCAPITALISM

What price the
genetic revolution?
By David Shenk

About a year ago, my wife phoned to say that something might be wrong with our unborn child. A blood test suggested the possibility of Down syndrome, and the doctor was recommending amniocentesis and genetic counseling. As it happened, I was almost finished writing a book about the paradoxical nature of information technology—the strange realization that more, faster, even *better* information can sometimes do more harm than good. When my wife's obstetrician reported the alarming news, it seemed as though the God of Technology was already looking to settle the score. The doctor, after all, was merely reading from a computer printout. Test results poured over us in a gush of formulas and statistics. My wife's blood contained such-and-such a ratio of three fetal hormones, which translated statistically into a such-and-such increased chance of our child having an extra chromosome, a forty-seventh, which can cause severely limited intellectual capacity, deformed organs and limbs, and heart dysfunction. The amniocentesis would settle the matter for certain, allowing a lab technician to count the fetus's actual chromosomes. But there was a dark statistical specter here, too, a chance that the procedure itself would lead to a spontaneous miscarriage whether the fetus was genetically abnormal or not. Testing a healthy fetus to death: many times, in the days ahead, I wondered if I could come to terms with that ultratemporary brand of senselessness. The computer thought it a risk worth taking: the chance of miscarriage was slightly lower than the chance of discovering Down syndrome. My wife and I put our faith in the computer.

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MAPPING GENES IS
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Few of these details will seem familiar to parents of children born before this decade; nor will any parents of children born after, say, 2010 face our specific predicament. The discoveries in the field have been generating one astonishing headline after another about genes related to Alzheimer's, breast cancer, epilepsy, osteoporosis, obesity, and even neurosis; the fetal-genetics revolution is now so accelerated that remarkable technologies become obsolete almost as quickly as they are invented. Although the "triple marker" blood test was invented in the late 1980s, it probably will be a historical footnote a decade or so from now. So will amniocentesis. Both will be replaced by a genetic sampling of fetal cells extracted from the mother's blood, a test that will be risk free for both mother and fetus. That's hundreds of healthy fetuses every year who will not be lost just for the sake of a genetic snapshot. We will know much more for much less.

But the odd question arises: Will we know too much? Fetal and embryonic genetic karyotypes may ultimately be as legible as a topographical map: *Your son will be born healthy; he will be allergic to cashews; he will reach five foot ten and a half inches; math will not come easily to him; in his later years, he will be at high risk for the same type of arteriosclerosis that afflicted his great-grandfather.* Here are secrets from the heretofore indecipherable text "The Book of Man," the wishful term used by researchers to refer to the complete translation of human genetic information that they one day hope to acquire. Such a discovery is what C. S. Lewis foresaw when he warned, in a prescient 1944 essay *The Abolition of Man*, "The final stage is come when Man by eugenics, by prenatal conditioning . . . has obtained full control over himself."

I'm jumping ahead, far beyond present facts and into the future. "The Book of Man" will not be finished for some time, if ever. But with the U.S. government's staunch support of the Human Genome Project, the \$3 billion mega-research sprint to map out and decode all of the estimated 100,000 human genes by the year 2005, genetic knowledge has suddenly become a national priority. It is this generation's race to the moon,

but we're not quite sure what we'll do when we get there; what the dark side looks like most of us don't particularly want to imagine.

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e're pursuing the human genome for good reasons, of course. With our new syllabus of genetic knowledge, we will become healthier and live longer. But even with the few facts that we now have, there is already cause to worry about the unintended consequences of acquiring such knowledge. If genes are the biological machine code—the software—containing the instructions for each person's development and decay, unlocking that code portends the ability to fix the bugs and even to add new features. When people worry aloud that we may soon be "playing God," it's because no living creature has ever before been able to upgrade its own operating system.

Lewis suggests that such absolute biotechnological power is corruptive, that it robs humanity of its instinctive duty to posterity. "It is not that they are bad men," he writes of future genetic "Conditioners." "They are not men at all. Stepping outside the *Tao*"—that is, outside the moral order as dictated by Nature—"they have stepped into the void." Although not yet close to a moral void, we do, even at this primitive stage of biotechnology, effortlessly step outside the *Tao*. Consider, for example, that when my wife and I went in for amniocentesis, we did so with the tacit understanding that we would abort our child if we discovered that he or she was carrying the extra chromosome; otherwise, there would have been no point in risking miscarriage. The fact that we did not abort our child, that she was born healthy, with forty-six chromosomes and four chambers in her heart and two lungs and two long legs, is morally beside the point. We had made our if-then choice to terminate. I suppose I'm glad I had the legal freedom to make that choice; I know, though, that

I'm still haunted by the odd moral burden it imposed on me: *Here is a preview of your daughter. If she's defective, will you keep her?*

We all want a world without Down's and Alzheimer's and Huntington's. But when the vaccine against these disorders takes the form of genetic knowledge and when that knowledge comes with a sneak preview of the full catalogue of weaknesses in each of us, solutions start to look like potential problems. With the early peek comes a transfer of control from natural law to human law. Can the U.S. Congress (which seems intent on shrinking, not expanding, its dominion) manage this new enlarged sphere of influence? Can the churches or the media or the schools? To mention just one obvious policy implication of this biotechnological leap beyond the Tao: The abortion debate, historically an issue in two dimensions (whether or not individuals should have the right to terminate a pregnancy), suddenly takes on a discomfiting third dimension. Should prospective parents who want a child be allowed to refuse a particular *type* of child?

From that perspective, I wonder if today's crude triple marker/amnio combination isn't just an early indication of the burdens likely to be placed on future generations of parents: the burden of knowing, the burden of choosing. I imagine my daughter, pregnant with her first child. The phone rings. The doctor has reviewed the karyotype and the computer analysis. He is sorry to report that her fetus is carrying a genetic marker for severe manic-depressive illness, similar in character to that of my great-uncle, who lived a turbulent and difficult life. Will she continue the pregnancy?

Or perhaps she is not yet pregnant. In keeping with the social mores of her day, she and her partner have fertilized a number of eggs in vitro, intending to implant the one with the best apparent chance for a successful gestation. The doctor calls with the karyotype results. It seems that embryos number 1 and 6 reveal a strong manic-depressive tendency. Will my daughter exclude them from possible implantation? The choice seems obvious, until the doctor tells her that embryos 1 and 6 are also quick-witted, whereas 2 and 3 are likely to be intellectually sluggish. The fourth and fifth embryos, by the way, are marked for ordinary intelligence, early-onset hearing impairment, and a high potential for aggressive pancreatic cancer. Which, if any, should be implanted?

Now add a plausible economic variable: Suppose that my daughter gets a registered letter the next day from her health maintenance organization, which also has seen the karyotype and the analysis (both of which they happily paid for). The HMO cannot presume to tell her which embryo to implant, but she should know that if she chooses to implant embryo number 1 or 6, the costs of her child's manic depression will not be reimbursed, ever. Now that the genetic marker is on the record, it is officially a "pre-existing condition"—in fact, the term has never been more appropriate.

Such are some of the specific scenarios now being bandied about by bioethicists, who, because of the Human Genome Project, are flush with thinking-cap money. Five percent of the project's funds (roughly \$100 million over fifteen years) is being dedicated to social and ethical exploration, an allotment that prompted Arthur Caplan, director of the University of Pennsylvania's Center for Bioethics, to celebrate the HGP as the "full-employment act for bioethicists." The Department of Energy, the National Institutes of Health, and the international Human Genome Organisation all have committees to study the social and ethical implications of genetic re-

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search. Popping up frequently are essays and conferences with titles like "Human Gene Therapy: Why Draw a Line?" "Regulating Reproduction," and "Down the Slippery Slope." While genetic researchers plod along in their methodical dissection of chromosomes, bioethicists are leaping decades ahead, out of necessity. They're trying to foresee what kind of society we're going to be living in when and if the researchers are successful. In Sheraton and Marriott conference halls, they pose the toughest questions they can think of. If a single skin cell can reveal the emotional and physical characteristics of an individual, how are we going to keep such information private? At what level of risk should a patient be informed of the potential future onset of a disease? Will employers be free to hire and fire based on information obtained from their prospective employees' karyotypes? Should a criminal defendant be allowed to use genetic predisposition toward extreme aggressiveness as a legitimate defense, or at least as a mitigating factor in sentencing?¹ Should privately administered genetic tests be regulated for accuracy by the government? (Currently, they are not.) Should private companies be able to patent the gene sequences they discover? Should children of sperm donors have the right to know the identity and genetic history of their biological fathers? The only limitation on the number of important questions seems to be the imagination of the inquirer.

Most fundamental of all, though, are questions regarding the propriety of futuristic gene-based medical techniques. Suppose for a moment that the power to select on the basis of, and possibly even alter, our genetic code does, as many expect, turn out to be extensive. What sort of boundaries should we set for ourselves? Should infertile couples be allowed to resort to a clone embryo rather than adopt a biological stranger? Should any couple have the right to choose the blond-haired embryo over the brown-haired embryo? Homosexuality over heterosexuality?² Should we try to "fix" albinism in the womb or the test tube? Congenital deafness? Baldness? Crooked teeth? What about aortas that if left alone will likely give out after fifty-five years? Should doctors instead pursue a genetic procedure that would give the ill-fated embryo a heart primed for ninety-nine years?

To address these questions, bioethicists need to determine what competing interests are at stake. If a father wants a blue-eyed, stout-hearted son and is able to pay for the privilege, which will cause no harm to anyone else, what's the problem? Consider the prospect of a pop-genetics culture in which millions choose the same desirable genes. Thousands of years down the line, the diversity in the human gene pool could be diminished, which any potato farmer can tell you is no way to manage a species. While public policy generally arbitrates between individual rights and social responsibilities, genetics raises a new paradigm, a struggle between contemporary humanity and our distant descendants.

¹ This question is not hypothetical. In February 1994, Stephen Mobley was convicted of murder and sentenced to death. In their appeal Mobley's lawyers argued that he had inherited a strong predisposition toward aggression. The appeal was rejected. But Deborah Denno, professor of law at Fordham University, believes that genetic evidence will be admitted in U.S. courts within a few years. "Given that so many people who commit homicides also have histories of families with relatives who are also incarcerated," she said in the *London Independent*, "I think it's just a matter of time before somebody tries it again."

² Dean Hamer, chief of the National Cancer Institute's gene-structure section, claims to have discovered genetic markers for behaviors such as sexual orientation, thrill seeking, and neurosis. "Psychiatrists making diagnoses and prescribing drugs in the future will look at patients' DNA, just the way they now ask about family history," Hamer has said. Follow-up studies have been inconclusive.



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The considerable support for legislation that would suppress some of these technologies draws its strength from a sense of moral indignation as well as from the fear of an alien future. In a *New Republic* essay entitled "The Wisdom of Repugnance," University of Chicago philosopher Leon Kass argues for a permanent ban on human cloning, a ban grounded not in hysteria but in moral principle. "We are repelled by the prospect of cloning human beings not because of the strangeness or novelty of the undertaking," he writes, "but because we intuit and feel, immediately and without argument, the violation of things that we rightfully hold dear."

On the other end of the spectrum, some scientists argue against any boundaries, proposing that whatever we can do to better ourselves is not only ethically appropriate but also imperative. "The potential medical benefits of genetic engineering are too great for us to let nebulous fears of the future drive policy," argues Gregory Stock, director of the Center for the Study of Evolution and the Origin of Life at UCLA. Stock and others contend that we know better than Nature what we want out of life, and we owe it to ourselves and future generations to seek genetic improvement as a component of social progress. In his article "Genetic Modifications," for example, Anders Sandberg, a young Swedish scientist and self-described "Transhumanist," not only recommends the removal of genetic "defects" and such less harmful "undesirable traits" as drug abuse, aggression, and wisdom teeth but proposes a wide selection of enhancements to benefit the entire race. Systemic improvements would involve reprogramming cells to be more resistant to aging, toxins, and fat. "Cosmetic modifications" would be the plastic surgery for the next millennium—alteration of hair color/texture, eye color, skin color, muscular build, and so on. Sandberg even fancies deluxe new features such as built-in molecular support for frozen cryonic suspension. We can chuckle now at the improbability of these ideas, but when we do we might also try to imagine how people might have reacted 150 years ago (before electricity, before the telegraph) to someone suggesting that people in the late twentieth century would routinely converse with people on other continents using portable devices the same size and weight as an empty coin purse. "It basically means that there are no limits," Princeton biologist Lee Silver remarked after the announcement of Dolly, the cloned sheep. "It means all of science fiction is true. They said it could never be done and now here it is, done before the year 2000."

The attitude within the ranks of the Human Genome Project community is, not surprisingly, quite a bit more conservative than Sandberg's. Nowhere in the project summaries will an affiliated researcher be found yearning publicly for a world filled with fat-proof, freezable people (although no one seems to have misgivings about any conceivable genetic engineering of pigs, cows, or other nonhumans). More modestly, the stated hopes for the application of gene mapping include a greater understanding of DNA and all biological organisms; new techniques for battling genetic diseases; a new prevention-oriented type of medicine; and a windfall for agribusiness and other biotech industries.

The fact that researchers are careful to limit their publicly stated goals reflects not so much a deeply ingrained social ethic, says Arthur Caplan, as a canny political awareness. "If uncertainty about what to do with new knowledge in the realm of genetics is a cause for concern in some quarters," he writes in the book *Gene Mapping*, "then those who want to proceed quickly with mapping the genome might find it prudent to simply deny that any application of new knowledge in genetics is imminent or to promise to forbear from any controversial applications of this knowledge. . . . [This] is the simplest strategy if one's aim is not applying new knowledge but merely to be allowed to proceed to acquire it." Caplan thus exposes a built-in tension between researchers and ethicists. Ethic-