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 ultracontemporary 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 THIS ERA'S RACE TO THE MOON, BUT WE DON'T KNOW WHAT WE'LL DO WHEN WE GET THERE

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.

We'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.

WILL MY DAUGHTER BE ABLE TO CHOOSE AMONG SIX EMBRYOS, EACH WITH HIS OR HER OWN STRENGTHS AND WEAKNESSES?

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-

Illustrations by Greg Spalenka