Tested on the book of life: Controlling the human genome

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The completion, or near completion, of the human genome project was announced with expressions of Promethean awe. The *New York Times* called the feat "a pinnacle of human self-knowledge." Other commentators referred to the new knowledge as the "Book of Life." President Clinton said mapping the body's sequence of genes was like "learning the language of God." And Dr. Francis Collins, who headed the U.S. government side of the project, said possessing the genetic code was like obtaining "God's instruction book" for humanity.

Of course, those schooled in the biblical tradition know that becoming like God is a treacherous occupation for mortals. Most commentators alluded to moral risks as well as practical benefits in knowing genetic secrets. Cracking the genetic code is indeed opening Pandora's Box—we have only begun to know what's inside, much less know what to do with it once we understand it.

The medical benefits of genetic knowledge are plain: doctors will, in theory, be able to locate the genetic source of diseases such as cancer, diabetes and Parkinson's, and to develop new methods of treating these diseases, perhaps even forestalling or eliminating them. A person's susceptibility to a disease could be learned years before the onset of symptoms, allowing for early medical treatment either by conventional means or by directly treating the offending gene.

Nonmedical insights may also emerge that have wonderful implications. Scientists are now pointing to the overwhelming genetic similarity of human beings and to the very slight differences related to race or ethnicity. Knowledge of the genome may deliver another blow to racial and ethnic discrimination.

But knowledge of the genome may well foster a new, more insidious form of discrimination—discrimination on the basis of genetic endowment. This kind of discrimination is likely to be more intractable because it will, in a sense, be deeply rational, based on the most fundamental knowledge of an individual's genetic inheritance.

So far, most of the concern has focused on issues of privacy and fairness: Who will own and control an individual's genetic information? Will employers and insurers be able to screen their applicants genetically and then turn down those likely to contract a disease or exhibit some undesirable trait?

But even larger moral risks are looming. Technology devised to treat serious illness will eventually be harnassed—by those with money—for genetic engineering. Dr. Robert Weinberg of the Whitehead Institute in Cambridge, Massachusetts, notes that the ability to manipulate genetic coding "will create the temptation to optimize one's offspring in terms of their genetic endowment." Who can doubt that some parents will want to reject fetuses that are genetically less than "optimal" in their eyes—perhaps lacking the gene for musical ability or high intelligence? And in such a climate, parents who choose not to abort a child judged by others to have significant handicaps are likely to be regarded as negligent or guilty of imposing unfair burdens on the rest of society.

Choices always entail temptations, and the ability to control the genome will present unprecedented choices and temptations. It will test much more than our sense of fairness. It will test our convictions about the purposes of life and about what it means to be human.