Genetic Renaissance in a Moral Dark Age

On June 26, 2000, President Bill Clinton and Prime Minister Tony Blair announced that the international Human Genome Project and Celera Genomics Corporation have both completed an initial sequencing of the human genome.

The announcement that the first draft of the human genetic blueprint is complete is very good news indeed. By knowing the sequence of the human genetic alphabet--the As, Cs, Ts, and Gs that make up our genome--we may be entering a genetic renaissance. We can have real hope that many of the nearly 5,000 genetically-linked disorders may be treatable in the foreseeable future. Some of those disorders may even be curable.

The bad news is that the science is being done in the context of what amounts to a moral dark age. Despite the advanced state of 21st century science, our moral sensitivities are at a very low ebb.

The fact that today's announcement comes in the thick of a battle between the U.S. government's National Institute for Human Genome Research (NHGRI), international partners in genome science, and the privately-owned Celera Genomics doesn't inspire confidence that we know how to handle the thorny ethical issues that are attached to the future of biotechnology. On the one hand, Francis Collins, head of the NHGRI, has argued that the human genome should not be the property of any private interest, while on the other, Celera Genomic's President Craig Venter has tethered his work on sequencing the human genome to his company's monetary interests. Do we want science to be done in service to humankind or science to be done in service to a few humans?

Even more frightening is the reality that through the genetic map we have access to the most intimate and powerful information one person can know about another person, but we cannot even agree about who counts as a human person. Those who make policy about the use of
genetic information cannot agree that unborn babies are human persons who at least deserve not to be unnecessarily harmed. They cannot agree that human beings and their body parts should not be owned through the patent process. They cannot agree that the disabled, infirm, and aged should be cared for in a dignified and humane manner, rather than being snuffed out by euthanasia. Technological progress like the Human Genome Project requires an equally stout set of moral and ethical guidelines to govern it. Unfortunately, we are a culture dominated by technological giants and ethical pygmies.

Additionally, the moral terrain upon which this genetic renaissance will be built is fraught with moral fault lines--fissures in which huge segments of the human population may fall. Genetic discrimination is a real and potentially devastating possibility. Yet, we have no national policy which prohibits discriminating against persons on the basis of their genetic code. Gene therapy without appropriate protocols of informed consent and research protection have already resulted in the loss of the life of young Jesse Gelsinger. Must others die needlessly? Food and agricultural biotechnology is being pushed down the throats of a highly suspicious public. We're one tragic incident away from a major backlash against the biotech industry.

This new era of genetic advancement may signal gargantuan leaps in the treatment and cure of human illnesses and diseases. It may, at the same time, mark a precipitous descent into immoral medicine.

Clearly, the public must be better educated and informed about the promises and perils of genetic engineering. Our elected officials must make it their business to hold town hall meetings and fund special educational opportunities for the purpose of honestly educating the populace about the potentials of this new era. The public relations spin on the Human Genome Project must give way to candid dialogue. If tax-payers are going to fund the research, they ought to know what is at stake. Unless public scrutiny is radically enhanced and unless ethical vigilance is rigorously applied, this glorious moment will be remembered in history as a very inglorious day of infamy.

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