LETTER *from the* PRESIDENT

August 2000

Dear Fellow Members:

Phil Ives is not a household name. His laboratory at Amherst College was not well known. He was already gray-haired when, as a little boy, I would scamper past his open door toward my dad's lab at the other end of the biology building. Feeling the hardwood floor vibrate, he would spin his chair around from his microscope, give me a wave and a smile, and turn up his hearing aid in case I wanted to say anything.

I never did. Dad's research in biochemistry was mysterious enough. Phil's work seemed even stranger. He sat among platoons of glass jars, the kind dairy cream once came in. Each had a white gauze top secured by a rubber band. Each gave off a peculiar, gelatinous odor. And inside each were swarms of fruit flies. I wouldn't have known what to say.

Phil, Dad explained, was a geneticist. He was a kindly soul–a New Englander who combined his love of research with a small farm where he and his wife raised hens and sold us our breakfast eggs. But genetics, in those days, wasn't on biology's cutting edge. It seemed to look backward to Gregor Mendel and his peas, not forward to the shining new chromatography equipment elsewhere in the building. Quaint, slow-moving, it seemed to lie somewhere between an academic discipline and a hobby.

How times have changed! Without question, the hottest science today is genetics: Witness the recent buzz over the Human Genome Project, which is well on its way to mapping the three billion chemical base pairs that make up humanity's genetic code. What's more, the creature whose genome has just been mapped so importantly by Dr. J. Craig Venter at Celera Genomics is *Drosophila melanogaster*–the fruit fly.

Phil would have been delighted. But wouldn't he also, I've wondered, have been concerned about the human implications of this science? Sitting alone hour by hour among his jars, that savvy New Englander must have pondered the ethics of his field. Only a decade before I knew him, after all, Dr. Josef Mengele and the Nazis at Auschwitz had been exploring the ghastly frontiers of eugenics–the science that seeks to create the more perfect human through manipulating its heredity. In 1953, Dr. James D. Watson and Francis Crick discovered the double helix model for deoxyribonucleic acid–DNA. By then a "green revolution" was already taking shape that would one day retool the genes in grains to feed India–thereby laying the groundwork for the protests now wracking Europe against genetically altered foods. Yes, the science is amazing. But so are the ethical ramifications, for good and bad.

By the time the search for the human genome was launched by the U.S. Department of Energy in 1988, the ethical implications of scientific research were coming more sharply into public focus. Exhibit A, of course, centered on the grisly results of the Manhattan Project, where science outran ethics in developing the atom bomb. So Dr. Watson, who became the first director of the Human Genome Project (HGP) office at the National Institutes of Health (NIH) in 1990, took a new approach. He insisted–perhaps for the first time in history–that some

funding for the Human Genome Project be earmarked for the so-called "ELSI" questions–the "ethical, legal, and social implications" of the work. Beginning at 3 percent, that proportion is now 5 percent, for a total of $58.3 million spent on ELSI at NIH since 1990.

Results? Measured by the output of studies, conferences, and insights, ELSI has been impressive. But it still has a distance to go. "The Final Report of the ELSI Research Planning and Evaluation Group," published in February of this year, notes that "there is . . . an underrepresentation of investigators from certain disciplines, such as economics, cultural and physical anthropology, and religious and moral philosophy." That lack of moral philosophers–ethicists–helps explain another underrepresentation. Scanning titles of 215 grants, contracts, and activities sponsored and funded by ELSI funding, we at the Institute found that only 8 percent appear to be exclusively or primarily concerned with ethics. Attention seems to be flowing toward the "legal" and "social" implications.

How can ELSI be brought to honor its initial "E" more fully? For starters, ethics can help us analyze these issues in more useful ways. Like ethical issues everywhere, those in the HGP fall into two broad categories. First are the moral temptations arising from humanity's misuse of this science. Second are the ethical dilemmas arising from its proper, intended use. The first set of problems are right-versus-wrong issues, calling for regulation. The second set are right-versus-right issues, requiring some of the deepest thinking that humanity can muster. Some right-versus-wrong examples:

1. Privacy and confidentiality. Everyone's genomic information, like any medical information, should be his or her own. There is a right to privacy that allows it to remain secret. If divulged for any purpose, it should remain confidential and unshared beyond its intended audience. Fear of intrusion and misuse–by, say, school districts wanting to know if your child has a "violence" gene–raises calls for tough regulation.

2. Discrimination or "genetic redlining." If genetic testing predicted that Mark will get a costly disease but Mary will not, employers would hire Mary instead of Mark. And insurers would surely cover her more cheaply than him. Yet if testing foresaw a shorter life expectancy for the mother than for the father, should divorce courts use that fact to award custody of the child to the father? And if Jason shows a genetic propensity for depression, should public resources help him more than Ralph, whose depression appears to be merely the result of an impoverished upbringing? Again, there will be regulation to ensure fairness.

3. Making monsters. Eugenics yearns to create a master race. But can't it also create a slave race–dumb, strong, fecund, and abjectly obedient to a tyrant's will in his or her mines, fields, or wars? Can recombinant DNA techniques someday reproduce Mengele's clone from a bit of his fingernail? At present, such sci-fi scenarios are remote. But public fear of them may generate efforts to forbid some experimentation as "wrong."

4. Who gets born? If some debilitating diseases are found to have identifiable genes connected with them, many would favor efforts to prevent the conception of children with those

genes. Yet if we go down that road, where will it end? What if tests on fetuses or on the newborn detect the "crime" gene, or the "potential alcoholic" gene, or even the "not the brightest bulb in the chandelier" gene? As the pressure for infanticide grows–especially in cultures facing severe population growth–so will the pressure for international regulation to prevent it.

5. Genocide. Genetically, humans are 99 percent identical to one another. The apparently huge differences we notice–in size, hairiness, skin color, musical prowess, and scores of other attributes–are the responsibility of only 2 to 10 million of the 3 billion nucleotide bases. Research into those differences may be helpful in understanding the wellsprings of talent, beauty, or courage. It might also be used to create a virus that only kills people who possess certain genes–the "Serb" gene, say, or the "Albanian" gene–while leaving others untouched. Here, there may be increasing calls for global treaties similar to those banning gas warfare.

Tough as they are, these issues aren't conceptually different from ethical issues that have always faced scientists. Since every new discovery holds the potential for unethical exploitation, regulation is always in the offing. Far more complex is the right-versus-right category:

Prediction. Is it better to know what the genes say will happen to the body than to live in ignorance? Academic tradition says, "Of course! Always know all you can." But is it preferable to live without fear, rather than to dread what science has said is inevitable but incurable? What does *incurable* mean, given the large number of medically inexplicable healings and remissions happening around us–not to mention the strong interplay of environment in shaping and even silencing genetic tendencies?

Fairness of access. If genetic treatments are developed, who pays for them? Should they, like the Human Genome Project, be subsidized by everyone's tax dollars, even though the end result may still be so expensive that only the rich can afford to be treated? Yet over time the prices might drop significantly–unless (under point #1 above) we have already decided not to discover the treatments at all.

History. Where did we come from? Genetic information may link us to present-day individuals living in other cultures who are part of our tribe or family. That linkage can tell us reams about our past. It can even tell Washington who the "real" Native Americans are so they can qualify for benefits due under the law. But since it can also tell a tyrant who the "real" Jews are so they can be persecuted, do we want to develop that information?

Normalcy. Who defines it? Is there a standard, average set of genes from which individuals vary a little or a lot? How much variation is too much? If couples will be able to select the genetic makeup of their offspring, will nobody choose red hair, green eyes, or freckles? Will the rich variety of humanity be diminished? Will "normal" come to mean "the only acceptable way"? If we are someday able to control the amount of diversity in the world, how much will we *really* want?

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What is a human? Medical interventions claim to be able to correct certain diseases by dealing, one at a time, with each patient. But what about interventions that eliminate the entire disease from the human scene? Changing one particular sand bar is different from changing the course of an entire river. Ought we change the river of life? Some would argue that we ought not play God and assert the human will over the divine–while others warn of unintended consequences overlooked by the incompleteness of today's science. Do we intervene or not? Which is right?

At the bottom of each of these right-versus-right questions is the much bigger issue: What kind of decision-making model will we use? How will we learn to identify the best moral arguments, determine the balance of opposing cases, and negotiate toward a higher right?

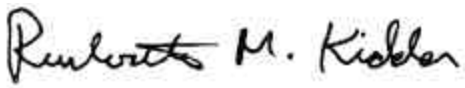
That, it seems, is where the Institute's frameworks have a role. The human processes for decision making are not well understood. One thing, however, appears obvious: Left unexamined, decision making too often becomes a matter of branding one side as "dead wrong"–so that, by default, the other side becomes the obvious choice. Lawyers are paid to do that in court. Voters often do it during an election. Some sports fans do it in every conversation. Result: We come to believe that "making a decision" means vilifying, denigrating, and deprecating. Those who see ethics as right versus wrong think that, by so doing, they're being ethical.

The Human Genome Project calls on us to rethink that model. Here, as elsewhere, the toughest issues slip right through the fingers of the right-versus-wrongers. That's why the decisions arising from genome research may strike us as among the most agonizing in human history. And so they will be, unless we cash in the I'm-right-you're-wrong model for something more useful.

Is there hope of such wholesale change in our reasoning patterns? I think so. After all, look at the change that has already occurred in a decade of ELSI programs. "In many ways," write the authors of the "Final Report," "the most profound impact of the ELSI research programs may be that the investigation of ELSI issues now has a level of legitimacy that it never had before…. More and more, the question appears to be not *whether* the ELSI issues ought to be considered alongside basic scientific questions, but rather why they are not being more aggressively studied. In this respect, a genuine paradigm shift in the relationship between science and ethics, law, and public policy may well be underway–at least in the field of genetics."

If that paradigm shift can take place, so can a shift in the way we make decisions. Unless, of course, we think somebody's going to find the decision-making gene that makes tough choices easy.

Sincerely,



Rushworth M. Kidder