The Human Genome Project: ethical and social implications*

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This article explores some of the potential moral and social ramifications of the Human Genome Project. Research on the human genome is generating important ethical and social questions of at least three distinct kinds. First, what genetic information should be generated, and who should control its dissemination and use? Improved diagnostic techniques such as presymptomatic testing, carrier screening, and prenatal screening can provide information that poses significant ethical problems for individuals, employers and insurance companies, and the medical and counseling professions. Second, what genetic procedures should be employed? The burgeoning ability to manipulate human genotypes and phenotypes through procedures such as gene therapy and enzyme therapy are leading to difficult questions about which manipulations should be permitted and which should be prohibited. Third, how will this new information change lives? Increasing claims about the relationship of genetics to ethically and politically significant traits and behaviors are challenging human self-understanding and the capacity of social institutions to respond adequately.

INTRODUCTION

When completed, the fifteen-year, $3-billion international Human Genome Project will have expanded genetic knowledge dramatically. The great investment made in this accumulating body of data is based on the premise that advances in biological research and medicine ultimately will benefit humankind. Scientific and technological advancements made in the three years since the official inception of the project have resulted in significantly improved productivity and accuracy in sequencing and mapping efforts. However, progress on the research front has been paralleled by an intensifying public debate over the promises and threats this new knowledge holds for society and for individuals. Building on a previous *Bulletin* introduction to the genome project and its major information tools and products, this article explores some of the potential moral and social ramifications of human genome information [1].

The notion that human genome research is beneficial is based on the assumption that the more scientists and doctors know about the genetic roots of healthy, normal human beings, the better they can predict, treat, and correct deviations. But several questions immediately arise: How and by whom are "normal" and "healthy" states determined? How and by whom are deviations diagnosed, classified, and judged? What decisions and actions can and should

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be taken in response to such diagnoses? Who makes these decisions?

The assumption that some deviations from normal behavior may be influenced genetically leads to another set of serious dilemmas. As stated by Carol Tauer, "the human genome project carries a dramatic metaphor: the notion that our genes are the program that determines who we are, and that when we know all the genes we will know the human being, both generically and individually" [2]. If, in fact, humans are their genes, then how can they be held morally and legally responsible for their tendencies, choices, and acts? Above all, will this new knowledge provide the ultimate yardstick by which to measure the nature, meaning, and value of human life?

The answers to these questions are likely to have a profound effect on many personal and social choices and practices. There must be reevaluation and possibly revision of medical diagnosis and therapy practices; reproductive, parenting, and counseling decisions; educational opportunities; employer-employee relations; the legal system; and insurance principles and policies. Underlying these deliberations will be issues of ownership, authorized uses, and accuracy of genetic information as well as access to it. These issues are of special interest and concern to information professionals.

The need to examine the ethical, legal, and social implications of the Human Genome Project was recognized in its formative stages. In 1988, Thomas Murray, Ph.D., director of the Center for Biomedical Ethics in the School of Medicine at Case Western Reserve University (and an author of this paper), was invited to testify about these issues before the U.S. Congress. In his testimony, he urged the Congress to direct a small percentage of the energy, creativity, and funding devoted to the Human Genome Project to the exploration of and preparation for some of the likely ethical, legal, and social consequences of this undertaking. The adoption of this recommendation and similar proposals put forth by other scientists resulted in the allocation of approximately 3% of the total budget of the Human Genome Project to investigation of these issues [3]. This is the first scientific project that from its inception has incorporated a commitment to studying ethical, legal, and social issues.

Another outcome of this decision was the establishment of the Joint Working Group on Ethical, Legal, and Social Issues (ELSI) of the National Institutes of Health (NIH) National Center for Human Genome Research (NCHGR) and the Department of Energy (DOE). Established in 1989, ELSI has been charged with the task of developing a plan for achieving one of the major goals of the project in its first five years, namely "Ethical, Legal and Social Considerations" [4]. In addition to ELSI and its broad-based mission, special task forces have been established to examine, evaluate, and formulate principles to guide policies and practices in specific areas such as insurance.

At the end of the first three of the anticipated fifteen years of the Human Genome Project, a number of issues already have arisen that have profound social and ethical implications. Moreover, a number of other equally, if not more perplexing, issues are visible on the horizon. The first has to do with the rapid accumulation of an enormous amount of information and questions relating to the use of this information by individuals and society. The second issue is, what kinds of manipulations of genetic material can be undertaken, and what limits are to be imposed on the ability to do so? Third, how should humans respond to likely changes in self-understanding—the understanding of who and what they are, why they do the things they do, what they are responsible for, and what is beyond their control?

THE GENOME INFORMATION CHALLENGE

One of the attractions of this work for information specialists is the preponderance of literary and library metaphors used to describe the human genome project. It is said frequently that the result of this effort will be the "book" of humankind. This book will have many variants and quite a few proofreading errors, but, nonetheless, it will be the ultimate book of our species. The genetic alphabet in which it is written consists of the four nucleotide bases—adenine, thymine, guanine, and cytosine (A, T, G, and C). The nucleotide bases are the letters of the genome alphabet. Combinations of three bases spell out "words" that specify amino acids, the building blocks of proteins, enzymes, and other crucial body chemicals.

Strung together in a specific order, these three-letter words make "sentences" that are genes. Genes can comprise tens or even hundreds of thousands of nucleic acids. They are organized into deoxyribonucleic acid (DNA) molecules, which in humans are compiled in forty-six chromosomes residing in cell nuclei. Each nucleated cell of the body contains three billion bases, or letters. However, not all of these letters are part of meaningful sentences, or genes. In fact, it is assumed that less than 10% of human DNA is actually used in making genes; that is, involved in creating useful products. This situation further complicates the task of reading and understanding the book of the human genome.

How far have scientists come in being able to decipher and make sense of this "book"? They have come as far as mastering the "alphabet," and they know something about how "words" are composed. What they currently are trying to find out is how sentences—that is, genes—actually function. Scientists also are becoming proficient in identifying and locating deviations from the norm in the meaningful

order of letters or words and in linking such "misspellings" or syntax errors with specific malfunctions. Furthermore, scientists are making some progress in devising editing tools, such as recombinant DNA technology, which can be used to correct some errors and even rewrite entire sentences.

GENETIC TESTING: NEW CHOICES, NEW CONCERNS

Disease testing

Although the ultimate goal of the Human Genome Project is to identify and sequence the entire complement of human genes, its immediate and practical objective is to identify the genes linked to diseases. As specific genes are discovered and deviations from their normal composition are identified, it will be possible to test and screen individuals for a growing number of diseases and abnormalities. However, the correlation between a diagnosed abnormality in a specific gene and the prospects for that individual's functionality and health is far from linear. In some cases, this person may actually be ill; that is, exhibit the symptoms of the disease associated with the gene. In other cases, however, the person may be carrying the gene yet not be showing signs of the disease. Diagnosis of the latter type of condition, presymptomatic disease, has been the predominant aim of genetic testing.

Huntington's disease, or chorea, was one of the first diseases for which such genetic tests were developed. Huntington's is inherited in a dominant fashion, meaning that if one of the parents is affected, then a child who inherits the gene will contract the disease. Huntington's chorea usually strikes in late adulthood, although there are exceptions. Persons afflicted with this disease develop movement disorders and profound dementia. The disease is progressive and ineluctable, and there is no treatment for it. Although the gene for Huntington's disease was discovered only recently, a test to determine whether an individual carries the gene has been in use for several years. The test is based on a method called "linkage analysis." It relies on the presence of specific, identifiable genetic markers positioned on the chromosome very close to the Huntington's gene that tend to be inherited together with it. By studying these markers in an individual and in a group of his or her close biological relatives, scientists can trace the patterns of gene transmission. This analysis can result in a prediction that is accurate 99% of the time about whether the individual will contract Huntington's.

However, the presence of a disease-related gene in an individual may have different implications, depending on the type of disease. In the case of Huntington's chorea, a positive diagnosis predicts that the individual, even if currently healthy, ultimately will display the symptoms and die of the disease. The situation is quite different for a growing number of other diseases that also have been linked with specific genes, such as breast cancer and colorectal cancer. In these cases, a positive test only indicates a predisposition to the disease, not its inevitable expression. Carriers of the BRCA-1 gene, which is associated with breast cancer and occurs in approximately 1 of every 200 women [5], have an 85% chance of contracting breast cancer in their lifetimes. The odds for being a carrier of the hereditary nonpolyposis colon cancer (HNPCC) gene are the same as for BRCA-1—approximately 1 in 200 persons [6]. The HNPCC gene, however, unlike the breast cancer gene, affects both men and women. Additionally, although this gene leads primarily to colorectal cancer, it also can result in several other cancers. With both cancer-related genes, as well as genes expected to be associated with heart and Alzheimer's disease, a positive test implies that the person is at higher risk of contracting the disease than is the general population, not that he or she is certain to become ill.

Carrier screening

There is still another scenario for using genetic testing to obtain information about the presence of a disease-related gene. This is carrier testing for recessive diseases. Whereas a single defective gene can bring on Huntington's disease, most of the common genetic diseases such as cystic fibrosis (CF), sickle cell anemia, or Tay-Sachs are recessive disorders. A person must be unfortunate enough to inherit copies of malfunctioning genes from both parents in order to manifest the disease. The parents, in this case, are carriers. Each has one "good" gene and one "diseased" gene but shows no symptoms. Approximately one in twenty-five people of European origin in the United States are carriers of CF. When a CF carrier and a non-CF carrier have children, none of these children is at risk. However, each child of parents who are both carriers has a one-in-four chance of having the disease. Approximately 1 in 2,500 births to people of European extraction is a child with CF.

Carrier screening is developing rapidly as a tool for detecting predisposition to disease. However, despite the potential benefits of such procedures in genetic counseling and parenting decisions, carrier testing in some respects has been more problematic than disease testing.

The announcement of the discovery of the CF gene was met with a great deal of misunderstanding and anxiety. Doctors were deluged by calls and visits from worried prospective parents who were wrestling with the decision of whether to be tested as potential carriers of the CF gene. This situation was not eased by the fact that commercial firms were able to produce

and sell the test quickly and were fiercely promoting it.

It rapidly became apparent, however, that the test is not 100% accurate. By looking at the CF gene in a large number of persons, it was discovered that there is not one "good" CF gene and one "bad" CF gene. More than 200 variants of the CF gene already have been discovered. Some are very common, while some are very rare. A half-dozen variants account for approximately 90% of all CF disease genes, but there are many others that a potential carrier would have to be tested for, one at a time. The actual CF test is a compromise—it only tests for the most common variants. Thus, it is possible that an individual testing negatively for CF still could be a carrier. In this case, testing can provide misleading information—a "false negative"—which may have devastating consequences.

Who will use disease testing?

When complete genetic screening becomes possible, perhaps more than 1,000 genes linked to abnormal conditions will be identifiable. It is expected that a person screened for all of them would show approximately 2% abnormality [7]. However, it is obvious that the interpretation of such abnormalities in relation to an individual's performance, health, and life expectancy varies greatly from disease to disease. It is also necessary to take into account significant differences in the accuracy of tests for different diseases.

Experience with genetic testing to date has provided insights into several other issues related to disease information. The first is the question of who decides whether to test a person for a specific disease. The answer is clear: Although the physician may have to determine whether a patient is at risk and inform him or her of the option of taking the test, it is the patient who makes the decision. A second issue is, if the decision rests with the individual, will men and women actually take advantage of disease testing?

Huntington's disease testing has provided some interesting and mixed answers to this question. The answer depends in part on whether a person really wants to find out whether they carry the gene for a specific disease. When the linkage test for Huntington's was under development, individuals at risk for the disease were asked whether they wanted the test or not. Overwhelmingly, they said they wanted it. However, when the test was made available, initially at no charge, only a relatively small percentage of those at risk actually came forward to take it.

This could be explained in part by the inconvenience associated with taking the test. However, responses from those specifically asked indicate that once the test became available, individuals encountered doubts about being faced with a potentially devastating truth. Because Huntington's remains essentially a death sentence and a particularly unpleasant one, it is understandable that many persons would choose not to know. The answer may be different with diseases such as breast or colon cancer, for which preventative measures can be taken and the chances for cure are relatively good. The nature of the disease is thus likely to have a significant effect on the actual use of screening tests once they become available.

The answer to the question of whether individuals will elect to undergo genetic testing also is related directly to the accessibility and availability of these tests. When the Huntington's test was still in the research phase, it was provided free of charge. Those who knew about it and physically could reach one of the testing sites were able to get it. But, when the test no longer was provided free of charge, cost became an obvious limiting factor.

Presumably, insurance could cover the costs in some cases. However, the Huntington's experience demonstrated that in reality, this is not an option. Individuals who knew they were at risk of Huntington's were often reluctant to ask their insurer to pay for the test. They feared that the resulting information might severely compromise their ability to obtain insurance in the future.

Employment and insurance concerns

The experience with Huntington's disease is indicative of growing social and ethical concerns. There are very real fears that access to genetic screening information by employers and insurance companies will result in new types of discrimination with respect to jobs and access to insurance. Persons whose genes indicate that they or their offspring are likely to suffer from a disability or a disease may find themselves barred from certain educational, employment, and insurance opportunities. The use of genetic screening by employers and insurers may have the effect of denying health care to those who are most in need of it.

How might information such as disease test results or carrier test results affect insurance policies and practices? Insurance is based on a catch-22 principle: If the insurer knows that a client is likely to need coverage, then the company either will not sell coverage or will overcharge heavily. In reaction to this practice, the AIDS epidemic caused a shake-up in the life insurance business.

In May of 1991, ELSI formed the Task Force on Genetic Information and Insurance to develop recommendations to prevent negative genetic information from blocking access to health insurance. The two-year mission of the task force was to characterize the problems of predictive genetic testing, to examine the likely impacts of this type of testing on health

insurance practices, and to propose socially useful solutions. The task force comprised physicians, biologists, geneticists, lawyers, ethicists, representatives from the insurance industry, associations concerned about genetic diseases, and an organization of state governments.

The final report of the task force was published in May 1993 [8]. The report contains several interesting conclusions. The first is that there is a prospective explosion of information on genetic health risks as a result of rapidly expanding capabilities for predictive genetic testing. The second conclusion is that it is practically impossible and morally indefensible to distinguish genetic from nongenetic disease risks in determining eligibility for health care coverage. For example, there is now ample evidence that cholesterol level is more a function of genetics than of eating and exercise habits. However, cholesterol level has been used as an index for health insurability and for determining health insurance rates. It generally has been accepted that higher insurance rates are justifiable when a higher health risk is the result of an individual's choice, such as decisions to smoke, ride a motorcycle without a helmet, or eat a high-cholesterol diet. However, if cholesterol level is largely genetic in origin, then applying this reasoning to this condition may not be sound.

A third conclusion of the report was that risk underwriting—that is, evaluating the likelihood that an individual would file a claim for health care coverage—should not be used in determining access to health care. The task force recommended abolition of individual risk underwriting in favor of a system of universal participation and universal access. The task force report has been delivered to the U.S. Congress and the White House. At this writing, plans are being made to engage national policy makers involved in health care reform in a dialog about the implications of genetic testing for the shape of a just and sustainable health care system.

Prenatal screening: parental choices and genetic counseling concerns

The fairly long menu of choices in prenatal screening currently available to prospective parents is likely to expand rapidly as more information is generated by human genome research. Some items that may be added to the list of screenable traits may be more problematic than they seem at first. Requests for prenatal screening to establish the sex of the fetus is a relatively widespread and disturbing practice, especially though not only in cultures that have a strong preference for males.

Moreover, there are likely to be new requests for screening that are even more perplexing or disturbing. For example, a gene for red hair has been identified and registered with the Genome Data Base/Online *Mendelian Inheritance in Man* (GDB/OMIM), which is the repository of human genome mapping information. Should parents be given the option of testing for this gene in their fetuses? As inconceivable as it may seem to end a pregnancy because of red hair, one can imagine prospective parents recalling the misery of their own childhood as redheads and insisting that they are not willing to inflict similar suffering on their offspring. (For the record, the authors regard red hair as at least as desirable and attractive as hair of any other color.)

An even more disconcerting yet not completely farfetched scenario is that of parents seeking prenatal screening because they specifically want a child with a genetic defect and will reject a normal child. This very case was cited by a physician who specializes in treatment of congenital deafness at a meeting of the American Society of Human Genetics. He said he had received such a request from deaf parents who refused to raise hearing children.

To what degree should parents be given such choices? What is the role of genetic counseling professionals? Genetic counseling has a tradition of value neutrality, or nondirectiveness. The ethical code of the profession requires that the counselor provide information and promote the client's free and informed choice. When testing focused exclusively on grave genetic diseases, the problems were much less complex. But now questions are being raised about whether neutrality is still appropriate. For a profession with a history of several decades, change is not likely to be a simple process. However, the role of genetic counseling must be reviewed. It may be desirable to allow or even expect counselors to evaluate the need for specific types of screening or the relative seriousness of a specific diagnosis and to offer more directive guidance than they traditionally have been inclined to give.

MANIPULATING HUMAN GENOTYPES AND PHENOTYPES

Although now lagging significantly behind advances in diagnosis and screening of genetic anomalies, a growing repertoire of techniques for prevention or treatment of these anomalies is likely to emerge from human genome research. There are two approaches to treatment or correction of a genetically determined abnormality or disease. The first, gene therapy, involves replacing the defective gene in a person's cells. The second type of treatment does not involve intervention in an individual's genetic make-up—that is, their genotype—but rather targets a specific feature or trait in their phenotype, aiming to reverse or modify the functional or physical expression of the

genetic anomaly. This is accomplished by providing the individual with one or more of the gene products, such as enzymes, that he or she is unable or only partially able to produce as a result of a specific defective gene.

Gene therapy

Building on advances in recombinant DNA technology, procedures involving genetic manipulation are under intense investigation as potential methods for curing persons with diseases as diverse as arthritis, leukemia, and AIDS. The first federally approved clinical trial of human gene therapy took place in September 1990 with two patients from the Rainbow Babies & Children's Hospital in Cleveland. The two girls were born without the ability to make adenosinedeaminase (ADA), an enzyme critical to a properly functioning immune system. The symptoms of this disorder are very much like those of AIDS, although the condition is not contracted as an infection but results from a defective gene. In a process called "transfection," white blood cells were removed from the girls, and a normal ADA gene was inserted into the cell nuclei. When the cells were put back into the girls, their bodies were able to produce normal ADA. Two years later, these girls who, prior to the therapy, had to live in highly protected environments, are leading normal lives [9].

This immediate and dramatic success exceeded expectations. It proved that immense power can come from mastering the genetic language. However, there are many technical obstacles to be overcome before gene therapy will be safe and effective. Additionally, there are thorny ethical dilemmas for society and individuals. It is easy to imagine situations in which adding what is presumed by some to be a "beneficial" gene or removing a "harmful" gene could be highly controversial. As with the ethical issues involved in prenatal screening, the question of distinguishing between treatment of a disease and the desire to manipulate certain human abilities or traits also may become problematic.

Manipulating phenotype

Another set of major social and ethical dilemmas related to genetic manipulations is not necessarily disease related. There will be a growing assortment of temptations for interventions and manipulations aimed at self-improvement. It will become increasingly difficult to decide which of these manipulations to undertake and which to forgo and to determine how and to whom the means of intervention should be made available and with what limitations.

For example, there has been a long-standing problem with the use by athletes of performance-enhancing drugs, particularly anabolic steroids. Athletes use performance-enhancing drugs to gain a competitive advantage. In the past, in certain sports, especially any of the strength sports—the discus, the hammer throw, the shot-put, weightlifting—most of those who competed successfully did so with the aid of drugs. It is already clear that genetic engineering will produce substances that can provide similar competitive advantages. Most likely, the desirability of these substances will extend well beyond the realm of athletics. They are also likely to be significantly more problematic from an ethical point of view than are anabolic steroids.

Genetically engineered human growth hormone (hGH), for example, has been on the market for several years now. Persons suffering from pituitary dwarfism can use it to increase their height and decrease limb distortions. HGH was discovered quickly by athletes who touted it as a super-steroid—more effective and producing fewer side-effects than the conventional drugs. It is apparent, however, that hGH may provide competitive advantages not only to those involved in athletic competition but also to any person and in everyday life. Height is an advantage in U.S. culture. Society is "height-ist." This is true particularly for men, although increasingly for women as well. Studies show that up to a certain limit (approximately six feet, six inches), the taller a man the greater the likelihood that he is in a high-prestige profession, received a higher starting salary, and was promoted more quickly [10]. Thus, it is not difficult or far-fetched to imagine that some individuals would want to take hGH or give it to their children to improve their chances for success in life.

As a society, what are the choices in making hGH available? Essentially, there are three choices. The first is to let the market determine the price, a policy that would make the hormone available to those who could afford it. The obvious result would be that the richer, the better-educated—the already advantaged—would also be taller and thus even further advantaged. This would polarize society by reinforcing height-ism. Such a scenario would not strike most observers as a desirable one.

A second option is to provide hGH to anybody who wants it. Who would benefit from this approach? Certainly the companies that make the hormone. But would individuals who took the hormone indeed be better off? There still would be taller people and shorter people, only everyone would be a few inches taller on average. The egalitarian approach to the distribution of hGH thus would result in absolutely no social benefit. Very much like the pervasive use of anabolic steroids by athletes in certain sports, ultimately, no one gains an advantage. There still are winners and losers. The winners are very likely to

be the same individuals who would have won without the drug.

The third option for distribution of hGH is to control its availability strictly, to provide it solely as a medication to those who suffer from conditions such as growth retardation. This is the approach taken with hGH at present.

GENOME INFORMATION AND UNDERSTANDING HUMAN BEHAVIOR

The third category of ethical and social issues arising from the Human Genome Project is related to challenges that the new body of genetic information will pose to self-understanding. Ironically, as human genome research progresses and new knowledge is gained, there will be a growing gap between what scientists know how to diagnose and what they know how to treat. Soon it will be possible to identify hundreds of genetic anomalies without being able to do much therapeutically about many of them.

The choices will vary from disease to disease. In the case of Huntington's, a person diagnosed with the condition can decide to change the course of his or her remaining life—cancel trip plans, decide to abandon or pick up a new project, move to a warmer climate—but cannot change the course of the disease. Positive test results for the colorectal cancer gene, on the other hand, can allow for more significant choices. Such results can be a strong impetus to evaluate habits and lifestyles, with the aim of minimizing the risks of contracting the disease. Additionally, several medical procedures can halt or slow the course of the disease. However, in all but the few cases of successful gene therapy, at this time, the choices fall short of a complete cure for any of these diseases.

The more genetic information accumulated, the more humans will be tempted to draw connections between genes and morally and socially significant aspects of life, such as character traits, the propensity to violence, intelligence, and creativity. People are likely to experience and, in fact, *are* experiencing a great overenthusiasm for genetic explanations for human differences. Human genetics is the example par excellence of a science of human difference. It will provide a virtually endless stream of reasons for regarding others as different, for not treating people as equals. How society deals with the evidence of genetic individual and group differences will be vitally important in the political future and, above all, the moral and legal future.

Were it ever to become possible to correlate specific behaviors with specific genetic differences, it would not be hard to imagine the use of this argument to justify the conduct of an individual being tried for a crime. Are there individuals who are genetically more prone than others to crime? If so, are they less responsible than are others for the crimes they commit? Furthermore, how does such a genetic link translate into a generalized prediction of how a specific socioeconomic or racial group may behave?

In May 1993, the director of NIH convened a Panel on Research on Antisocial, Aggressive and Violence-Related Behaviors and Their Consequences to consider, among other questions, research on the genetic basis for violent behavior. In fiscal year 1992, the NIH spent approximately $53.7 million on research related to violence and antisocial behavior [11]. This research has spanned a broad array of topics, from treatments for post-traumatic stress disorder to techniques for rape prevention to the biology and genetics of aggressive and impulsive behaviors. The panel was asked to evaluate this body of research critically and to advise the NIH regarding its ethical aspects. The panel made its report in April 1994.

Linking violent behavior to a gene that may be more prevalent in a specific group is a politically sensitive issue, as one might guess. Violence is only one example of such a trait. There will be numerous occasions when certain people will wish to use claims about the genetics of human behavior to advance a particular personal or a political agenda. Society had better be conscious of these issues and prepared to try to deal with them wisely.

CONCLUSION

In looking at the sequence of nucleotides that make up the map of the human genome, some might interpret it as humanity reduced to nothing more than its genetic language. However, this point of view is equivalent to saying that a wonderful musical piece, such as Barber's Adagio for Strings, is no more than a sequence of black marks on white paper. Anyone who has heard this piece and knows how moving it can be understands that what makes it so wonderful is the performance. Similarly, each person is a performance of the human genome. Some are more interesting than others, some have more flaws than others do, but each is a unique performance. Just as Barber's music loses nothing of its magnificence by being represented as a sequence of notes, writing out a string of letters representing a genome does not reduce human significance.

Individual futures are not dictated by genes. Nor is the future of society determined by some inexorable machine of genome science. Society has recognized that the new science of human genetics has profound implications for how humans shall live. And society has accepted the initial challenge by addressing the ethical, legal, and social issues posed by genetics. The next few decades will reveal whether society is up to the greater challenge of preserving

what is best about individuals, institutions, and culture while integrating modern genetics into human lives.

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