THE HUMAN GENOME PROJECT:

ETHICAL IMPLICATIONS AND ISSUES

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Table of Contents

1. Chapter One: The Beginning of a New Era.....1
2. Chapter Two: The Technology of a New Era.....15
3. Chapter Three: Knowledge Before the Fact.....24
4. Chapter Four: Knowledge Without Treatment.....33
5. Chapter Five: Engineering Ourselves and the Future.....49
6. Chapter Six: Contemporary Determinism and Reductionism.....68
7. Chapter Seven: The Road Ahead.....78
8. Selected References.....84

Chapter One: The Beginning of a New Era

"We used to think our fate was in our stars. Now we know,
in large measure, our fate is in our genes."
-James Watson[1]-

The discovery of the double helix in 1953 by James Watson and Francis Crick opened the door to amazing investigations and discoveries. In recent years, knowledge of DNA's structure has led to expanding capabilities involving the genetics of living beings. From the mechanism of DNA replication to genetic inheritance, the elucidation of DNA's structure has drastically affected our ability to understand the inheritability of characteristics. Through the manipulation of genes, humanity can create genetically enhanced crops and livestock. We have also learned to clone genes that code for medically useful proteins. In the past decade, attention has moved from the genetic code of other living beings to that of human beings. We have known for years that genes control many characteristics from eye color to physique. Many diseases, like Turner's and Huntington's, have genetic origins. Though it continues to be debated, several scientists have contended that even behavioral characteristics such as aggressiveness, depression and homosexuality are influenced by our genetic heritage. We also know that carcinogens and mutagens increase the chance of genetic mutations. But how can we study the real effects of such substances in changing the DNA sequence if we do not know what an individual's sequence looked like before exposure to carcinogens and mutagens? Additionally, if we can learn the genetic code for conditions like Huntington's disease, cystic fibrosis, and muscular dystrophy, we

might be able to detect such conditions beforehand and correct them before such conditions developed. To do these things, a template of all the genes in the human body, the human genome, is required.

Unveiling the human genome is ultimately the goal of the Human Genome Project. But how did such a project get started? What is entailed in such an enormous project? Most importantly, what are some possible consequences of achieving our goal? What will people do with the information and understanding gained and how will this affect the rest of humanity? In the past, we have often stepped forward without looking at the implications of our actions. The Manhattan Project stands as one example of what can happen when humankind jumps before it looks. Humanity marveled that nuclear power could provide energy while producing no pollution. Unfortunately, this notion proved not only to be untrue but occasionally the nuclear process has been deadly. Thus, it is important for all human beings to stop and look at the possible consequences of the applications of the Human Genome Project. In the process of examining the Human Genome Project, it is important to look not only at the science involved but also at the ethical, legal, and social issues raised. Although an attempt will be made to look at all aspects of the Human Genome Project, this paper will focus on the ethical issues from a philosophical perspective keeping in mind the ideas of human dignity, respect, utility, and rights.

The Human Genome Project is an international affair. The human genome is not unique to Americans but to the rest of humanity as well. Thus, the information

discovered in one country will be important around the world. However, special attention will be paid to the project and its implications here in the United States. The two agencies that have been instrumental in the development of the U.S. Human Genome Project are the United States Department of Energy (DOE)and the National Institute of Health (NIH). Though it may seem strange that the DOE is involved, the DOE has had a long history of involvement in human genetics. Since the arrival of nuclear energy, they have been interested in the effects of radiation on the human body. Sequencing and mapping of the human genome would only make such studies by the DOE more reliable. Though the information gathered is to be used in determining the side effects of nuclear energy and waste, the information could conceivably be utilized to make more devastating weapons.

The DOE and the NIH began work on the human genome separately. In 1983, the DOE began by setting up the Gene Library Project. However, at this time it was not a full-fledged plan to sequence and map the entire genome. The real idea of sequencing the human genome began in 1984 at the University of California, Santa Cruz. At the time, it was only a brainstorm of molecular biologist Robert Sinsheimer. Then in 1985, he proposed the idea at a meeting of prominent scientists. Many of these scientists were highly skeptical: they questioned the scientific value of such an enormous project, and they wondered if the tremendous costs that would inevitably be involved might not justify such a project especially since the practicality of the information to be obtained was still undetermined. Others opposed the project because of possible consequences. They feared that

the information gained might be misused. Though nothing ever directly came of this proposal, it caught the attention of many influential people including Renato Dulbecco (a Nobel Prize winner in biology) and James Watson. Soon, university scientists were petitioning the reluctant NIH for funds to begin research. With the end of the cold war, Charles DeLisi, head of the Office of Health and Environmental Research, suggested switching from nuclear research to molecular biology. In March of 1986, he organized a meeting to endorse the idea of sequencing the human genome. The DOE, with its large monetary support, seized the opportunity to begin work on such a project.

Like the DOE, Watson felt that such a project was not only worthwhile but feasible. However, Watson, like many other scientists, was suspicious of the project being left in the hands of the bureaucratic DOE. Due to the debate over the project, several different agencies including the U.S. Congress's Office of Technology Assessment, DOE, Howard Hughes Medical Institute, and most importantly the National Research Council (NRC) initiated investigations. The NRC came to the conclusion that sequencing the human genome appeared promising but stressed that the expense should be contained. The NRC also suggested expanding the scope to include nonhuman species that could be used as reference checks. Momentum was gathering quickly, and in December of 1987, the NIH received $17.2 million to be used for human genome research while the DOE was allocated $12 million from the U.S. government. In February 1988, the NIH held a meeting that changed the emphasis of the project from sequencing of the human genome

to mapping and understanding of the human genome. A couple of months later, Watson was asked to run the NIH research. On October first, Watson was officially named as Associate Director of the Human Genome Research at NIH with a budget of $28.2 million for 1988. Also in 1988, researchers worked to form the Human Genome Organization (HUGO) to help coordinate the international efforts. Unfortunately, like NATO, HUGO has no real influence because it gets no independent funds. Shortly thereafter, the NIH and the DOE agreed to cooperate on the project. From here the project exploded with budgets of $60 million for 1989 and $108 million in 1991 for the NIH alone. However, it quickly became apparent that the current techniques for mapping were not only too expensive but also too slow. At the time, the cost for deciphering each base was $1 with an estimated three billion bases in the human genome. Therefore, in the summer of 1989, representatives from the NIH and DOE along with other experts met to draw up a five-year plan for the Human Genome Project.[2]

The five-year plan explained the general intentions of the U.S. Human Genome Project. Through this plan, it became clear that there were several related overall goals driving the project. These general goals included: "construction of a high-resolution genetic map of the human genome; production of a variety of physical maps of all human chromosomes and of the DNA of selected model organisms, with emphasis on maps that make the DNA accessible to investigators for further analysis; determination of the complete sequence of human DNA and of the DNA of selected model organisms; development of capabilities for collecting,

storing, distributing, and analyzing the data produced; and creation of appropriate technologies necessary to achieve these objectives."[3] In order to break up the immense project of unveiling the human genome into smaller tasks, the committee set several initial goals. These initial goals included the following: "expansion of the genetic map to a resolution of one centimorgan (a recombinant unit of approximately one million base pairs); construction of complete physical maps of the DNA of certain model organisms and beginning the construction of physical maps of human chromosomes; development of new technology to increase the efficiency and accuracy, and lower the cost, of physical mapping and of DNA sequencing."[4] In addition, the plan set specific goals to be achieved in five years.

Goals were set in the following areas: mapping and sequencing the human genome, mapping and sequencing the genomes of model organisms, data collection and distribution, ethical, legal, and social considerations, research training, technology development, and technology transfer. More specifically, after five years the committee expected a complete map of the human genome accurate to within five centimorgans or five million base pairs. They also wanted a physical map of all human chromosomes containing markers at 100,000 base pair intervals. In connection with these goals, technology for DNA sequencing was to be improved so that the cost of sequencing would be decreased from $1 per base pair to $0.50 per base pair. Genomic maps of mice and other select organisms like E. coli would also be needed. Software and databases capable of handling the immense amount of data generated from the project would be required. Among other things, these

databases would have to be able to support large-scale mapping and sequencing projects, comparison of data, and interpretation of the information. Because of the many ethical, legal, and social implications of the information generated by the Human Genome Project, programs were necessary to understand the issues and develop initial policies concerning the issues identified. Since the project of unveiling the human genome involved much tedious work, research trainees would be needed to help speed the process. The aim was to have 600 trainees per year at the end of five years. Besides the technological improvements mentioned above, it would also be necessary to cooperate more closely between the independent research laboratories here and abroad.

Due to advances in technology and the swift progress of the project, the NIH-DOE met to review the progress and direction of the project in 1993. This time the meeting focused on updating and extending the original five-year plan considering the newer technology and information available. At the meeting the following was goals were decided: 1) Within the area of genetic mapping, the 2-5 centimorgan map was to be expected by 1995. 2) The development of new technology for rapid genotyping, marker use, and mapping would continue. 3) Expectations for the physical genomic map would remain the same. 4) By the end of 1998, the sequencing capacity is expected to be fifty million base pairs and increased efficiency. 5) The sequence of E. coli and Saccharomyces cerevisiae should be complete and that of C. elegans close to completion. 6) Methods for gene identification and map placement also are to be developed. 7) The development

of efficient software and databases must continue as before. 8) The Ethical, Legal, and Social Issues program (ELSI) must work on its issues and on the education of the public and professional sectors of the population. 9) Though the original goal of 600 trainees per year proved to be unrealistic, encouragement of future trainees was seen as necessary. 10) Moreover, besides the seven areas of goal setting in the original plan, an area concerning outreach programs was added. The purpose here was to insure the sharing of genomic information within six months of any discovery.

Scientists and others involved in the Human Genome Project must be given credit for recognizing the importance of addressing the ethical, legal, and social implications of their research. By starting the debate and investigation under the guidance of ELSI now, we will hopefully have many answers to the issues by the time the information from the project is applicable. It is of major importance that the scientists involved in the Human Genome Project cooperate with those on the ELSI board. The only way that the issues can be accurately answered is with full knowledge of the technology involved and the possible uses of the data.

Initially, the NIH National Center for Human Genome Research proposed nine different issues associated with the Human Genome Project. However, these issues were not posed in any type of order. Thus, I find it more valuable to group the issues into three different levels, individual, societal, and species (as George J. Annas and Sherman Elias do in Gene Mapping). The first level of division is the

individual/family. Here we find the issue of collecting the genetic information through the process of genetic screening. This includes debate about what information can be collected, how the information is collected, who may collect the information, for what purposes may screening be done, how should the results be released and to whom, the commercialization of the technology, and the consequences of the resulting information on the individual and the family.

More important to the process of genetic screening are the issues of autonomy and confidentiality. The process of genetic screening is further complicated by the fact that every disease poses different problems. Not every disease has the same influences as the next. Thus, one standard formula will not be adequate. The frequency of a disease in particular groups and the treatment or lack of treatment available stand as examples. It appears certain that federal and state legislation will be required to curb the problems of confidentiality and discrimination caused by genetic screening.

DNA "gene banks" also pose a problem. DNA is a stable compound and does not degrade readily with time. Thus, DNA samples in the form of sperm, egg, blood and the like could be stored and analyzed later as the technology develops. Tissue samples could also be taken from corpses and analyzed. The problem occurs when a person's DNA sample is put into a gene bank without their consent. And even if they consent, no regulations govern the practices of gene banks. There is always the problem of confidentiality especially if gene banks merge or go out of

business.

Societal issues compose the next level of discussion. Three main issues appear at this level. The first issue is that of population-based screening, which could help eradicate a genetic condition or give a frequency of the condition in society. This is especially problematic when such screening is mandatory and the results are not kept confidential. Again, the issues of autonomy and confidentiality arise. The allocation of resources and the commercialization of screening processes poses other problems. How much of the gross national product are we willing to spend on the Human Genome Project? Of equal importance, who will have access to genetic screening? With the current health care system, only those people with insurance or the funds to pay will have access. This would leave the screening process out of the reach for many individuals. If insurance companies obtain access to screening results and use this information to determine eligibility for insurance, then many more individuals would join the ranks of the uninsured and underinsured. The end result could easily be the development of a genetic underclass.

The last issue in this level, eugenics, is by far the most important issue. Eugenics refers to the use of genetics not simply to prevent and treat but also to enhance and "improve" the genome. There is a legacy of eugenic attempts in our past, though now eugenics will be possible at a different level. The history of eugenic practices is not limited to Nazi Germany, though it probably stands as the

most widespread and drastic. For example, in 1927, the U.S. Supreme Court said that "eugenics by involuntary sterilization of mentally retarded was constitutionally acceptable based on utilitarianism."[5] The implications of the Human Genome Project at the level of eugenics are especially important in countries like China where couples are only allowed to have one child. What haunts us is the fact that we might soon have the capacity to practice eugenics at the most basic level, on the genes themselves. As the U.S. Office of Technological Assessment noted, "New technologies for identifying traits and altering genes makes it possible for eugenic goals to be achieved through technological as opposed to social control."[6] Conditions viewed as dehabilitating could be eradicated as could genes for shortness. Entire gene pools could even be eliminated.

The final level of discussion is that of species issues. Again with the past as an example, we can see how new technology not only changes our abilities but also the way in which we think. The telescope not only allowed us to see the stars but also helped us to change our view of the solar system. Electronics and the automobile not only opened new opportunities but changed the way we live. Transportation has allowed us to move around more freely. Traveling across the country is no longer a half-year process. Electronics is allowing us to keep in touch with others so easily that while we may be many miles away it no longer seems so far. It is important to note the effects that technology has on us especially when the technology being developed has such far reaching applications. Furthermore, the

Human Genome Project, by reducing humanity to a sequence of nucleotides, allows for the ultimate in deterministic views. Such a view of reality results in the loss of responsibility for our actions. By viewing ourselves as a sequence of molecules, we set ourselves up for a society where human beings are manufactured-to-specifications as in Brave New World. In Brave New World, Aldous Huxley describes a world where people are born in test tubes. They are cloned and manipulated both physically and mentally. They are exposed to certain environmental influences as embryos to create people with certain talents or hindrances. Compared to the possibilities opened by the Human Genome Project, this is a crude form of eugenics.

In the end, the Human Genome Project will reduce the human body into six billion tiny organic pieces. Additionally, because many will try to link genes to behavioral and psychological patterns, the person will be reduced as well. People have always tried to simplify things, but this stands as the ultimate in reductionism. The activities of the human being, its actions, emotions, thoughts, behavior, diseases, will be reduced to a series of codes. Many people will try to explain all human activity in terms of a code. Yet, "we know that most diseases and abnormalities are social constructs rather than facts of nature."[7]

There is no such thing as a "normal" human genome. The genome revealed, called HUGO, will be a composite of many different individual genomes since DNA from more than one source will be used. Many critics and even supporters worry

that HUGO will be overwhelmingly Caucasian and male. Though it is necessary for HUGO to be male, since both the X and Y chromosomes must be uncovered, there remains no reason for HUGO to be Caucasian. In fact, if HUGO were to represent the "original" human, HUGO would be far from predominately Caucasian. Nevertheless, many of the scientists working on the project are Caucasian males, and historically, researchers tend to focus on themselves and people similar to them when carrying out research. Thus, the fear that HUGO will be predominately Caucasian may well be justified.

The Human Genome Project will, in all likelihood, be completed before we have answered many of the ethical, legal, and social implications surrounding the consequences of applying the information gained. However, it is important for everyone to begin discussion of these issues now. Though the Human Genome Project will undoubtedly bring with it great potential for the relief of suffering as well as disease prevention and treatment, there may be unwanted side effects. If we can anticipate even some of them, we could prevent or at least lessen their harm. In the process of my investigation, I hope to open the way for a more complete understanding of the issues and problems raised by the Human Genome Project by drawing from the works of such contemporary philosophers as George J. Annas, Sherman Elias, Tom Wilkie, and Arthur L. Caplan, who have written extensively about the Human Genome Project.

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Chapter Two: The Technology of a New Era

"Each new power won by man is a power over men as well. Each advance leaves him weaker as well as stronger."
-C.S. Lewis[1]-

Complex theories, techniques, and technology surround the Human Genome Project. Therefore, a short history of pre-twentieth century speculation regarding genetics and a review of contemporary genetic science would be helpful to better understand where the project is coming from and where it is headed. An explanation of the technology and processes is also important so that claims and applications of the technology can be grasped.

The actual Human Genome Project is relatively new, having only begun in 1989. However, many ideas from which the project is built upon are quite ancient. The concept of inheritable traits can be traced back to the Greeks. Aristotle incorrectly proposed that offspring came from egg and sperm formed from particles called pangenes. These particles came from throughout the body. This theory, known as pangenesis, was used by Charles Darwin in 1859 in his formulation of the natural selection hypothesis and evolution. According to this hypothesis, competition between organisms caused some members to die. Through the process of natural selection, genetic information that is beneficial will continue to be inherited, whereas that information which is detrimental will be removed. The driving force behind natural selection is the environment. As the environment changes, the characteristics of benefice also change causing a population to evolve.

Unbeknownst to Darwin, Gregory Mendel, an Augustinian monk, developed an idea of inheritance that involved particles called genes at about the same time. His theory, now known as Mendelian genetics, serves as the foundation for genetics. In his theory, Mendel believed that all cells contained genetic matter which was passed on to the offspring. Since then, it has been determined that this genetic matter lies on structures termed chromosomes in units called genes. Offspring were formed from special cells that contained only one copy of each gene while normal cells contained two copies. These special cells now called germ cells would unite, one from each parent, to form the offspring. Since each gene came from a different parent, the genes could "code" for different phenotypes of the same characteristic. One of the "codes" would hold precedence over the other. Thus, came the idea of recessive and dominant genes. For example, one gene in the pea plant might "code" for a smooth pea while the other "coded" for a rough pea. If the gene for smooth peas was dominant, then the peas on that plant would be smooth. Although many characteristics and diseases follow Mendelian genetics, we have since discovered that many do not. Instead, they involve more complex mechanisms of inheritance.

In this century, scientists, particularly molecular biologists, began to look for the actual processes and structures of genetics. What exactly in the cell corresponded to the chromosome and genes? How did replication and expression of these structures occur? At the beginning, the investigation concentrated on the idea of genes as a special kind of protein. Later, it became obvious that the

structure of chromosomes could not be protein but instead was deoxyribonucleic acid (DNA). Though DNA was not a new discovery at this time, the thought of DNA containing the information for life was new. Through a combination of x-ray crystallography, model building, and stereochemistry, the structure of DNA became evident in 1953 through the combined efforts of Francis Crick, James D. Watson, Maurice Wilkins, John Steinbeck, John Kendrew, Max Perutz, and Rosalind Franklin.

Today, the structure of DNA is generally accepted as that of a double helix consisting of a sugar backbone on the outside and four different bases in the middle. Two of the bases are purines: adenine and guanine. The other two are pyrimidines: thymine and cytosine. The bases always pair up so that adenine pairs with thymine and guanine with cytosine. Each DNA strand is complementary to the other. Thus, if the sequence of bases of one strand is known, the other strand can be synthesized. Such an arrangement allows for semi-conservative DNA replication where the double helix is separated and two identical copies made, one from each of the DNA strands. Consequently, only one strand of DNA has to be sequenced in order to determine the entire sequence of a chromosome.

Scientists have shown that one strand of DNA, the sense strand, is used as a template from which to make ribonucleic acid (RNA) in a process known as transcription. Unfortunately, the process of transcription is not this simple since the same strand is not always used as the sense strand. There are three main differences between RNA and DNA. DNA is deoxygenated and RNA is not. RNA

is single stranded not double stranded. RNA uses uracil in place of thymine. From the messenger RNA (mRNA) that is transcribed, proteins are synthesized through translation. Before the process of translation occurs, the RNA is modified so that some information is removed. The sequences excised are called introns and serve no coding function. It has been estimated that upwards of 90% of the human genome is excised as introns.[2] The material that remains is called exons and comprises the mRNA that is translated. In the lab, this mRNA may be used to synthesize complementary DNA (cDNA) which is identical to the original DNA though it lacks introns. Therefore, mRNA can be used to determine the sequence of expressed genes requiring less time and money.

The genes of the human being are organized into sets of 23 chromosomes with each individual having two sets. Of the 23 chromosomes, twenty-two are identical pair members, they code for the same genes though their sequences may not be identical. The other is a sex chromosome, and the set can exist as either XX or XY. Normally, the male contains an X and a Y, whereas the female has two X's. The goal of the Human Genome Project is to elucidate the sequence of DNA and to place it within the genome on and within its respective chromosomes. Eventually, this information will be applied to human biology and medicine. As of the Human Gene Mapping Workshop in Oxford during September of 1990, approximately 1,900 genes had been fixed to specific chromosomal locations with more than 4,500 DNA segments mapped to specific chromosomal sites.[3]

The chromosomal map shows the designated positions of genes or DNA

fragments within in their respective chromosomes. Distances between genes or DNA fragments are measured in base pairs. In order for such a map to be made, the DNA must first be cut into pieces by restriction enzymes. Restriction enzymes work by recognizing short specific segments of DNA where the DNA is then cut. The size of the recognition site is proportional to the size of the resulting DNA fragments. By using more than one restriction enzyme, the DNA can be cut into smaller fragments. These fragments are marked with an observable label whose position is determinable when bound to chromosomal DNA. To determine the position of only expressed regions of DNA, cDNA may be used instead of DNA. The chromosomal map is the lowest-resolution physical map.

High-resolution maps are compiled by two different techniques. The top-down technique cuts a single chromosome into large pieces by means of restriction enzymes. These pieces are ordered and subdivided with the smaller pieces being further mapped. The resulting map remains fairly continuous with fewer gaps than others. Unfortunately, the resolution is much less and may not even be useful in pinpointing specific genes. The bottom-up technique requires the cutting of the chromosome into very tiny segments which are cloned and then ordered to form continuous DNA blocks called contigs. The end result is small overlapping contigs representing complete chromosomal segments. This type of mapping is useful for elucidating genes to a localized area.

Before a chromosome can be mapped, the chromosomes must be separated and obtained in pure culture. Currently, two methods of separation are utilized. The

first, flow sorting, separates the chromosomes according to size once they have been isolated from the cell in the condensed form. The chromosomes then pass through a laser beam one at a time. An analysis on the amount of DNA present is done and the chromosomes are directed to certain collection tubes. The other technique involves the fusion or hybridization of human cells with rodent tumor cells. Called somatic cell hybridization, human chromosomes are allowed to be lost from the hybrid cells until only a few remain. These remaining few are cloned.

For sequencing of a gene to occur, the DNA fragments must first be amplified. This can be accomplished by either cloning or the polymerase chain reaction (PCR). Cloning involves the manipulation of transduction and transformation processes. In this way, DNA fragments isolated by restriction enzymes are incorporated into a carrier or vector. The vector is introduced into an appropriate host cell where it is replicated along with the host DNA. Besides bacteria, viruses and yeast cells are also used for vectors. This process provides unlimited material in an unordered fashion.

PCR can amplify desired DNA sequences many times in a matter of hours. The process uses the abilities of a special polymerase enzyme, DNA polymerase. Primers used in PCR are highly specific. In order for the DNA polymerase to work, the primers must bind to specific regions of the DNA strands. The primers are added in excess to heat denatured DNA, which is DNA heated to a temperature sufficient to cause separation of the strands. As the mixture cools, the primers bind to the target DNA and DNA polymerase is added. DNA polymerase extends the

primers down the length of the target DNA. The process is continued over and over again to obtain many DNA fragments of the same sequence.

Two different sequencing approaches are available for the sequencing of DNA fragments. Both use gel electrophoresis to produce extremely high resolution DNA separations. The Maxam-Gilbert technique or the chemical degradation method cleaves DNA at specific bases by means of chemical agents. The resulting fragments of different lengths are then analyzed by gel electrophoresis. Sanger sequencing, also called chain termination or dideoxy method, produces fragments of different lengths by the use of enzymes. This occurs by the stoppage of DNA replication at positions occupied by one of the four bases. Due to the great expense and time involved in current sequencing procedures, only small regions of immense interest have been sequenced. New mapping and sequencing techniques are constantly being developed through the study of nonhuman genomes like the bacterium Escherichia coli, the yeast Saccharomyces cerevistae, the fruit fly Drosophila melangaster, the round worm Caenorhabditis elegans, and the laboratory mouse Mus musculus. Presently, strips of DNA containing medically useful sequences are decoded every week. Soon the sequence of a new gene will be delineated every hour. By the end of 1994, a genetic map (a map that gives information about the recombination and separation of known marker sequences between generations) of the entire genome was finished and 95 percent of the genome has been physically mapped (a physical map locates a gene or region of interest on the chromosome). Expectations for a physical map containing markers

every 100,000 bases by the end of this year seem reasonable.[4]

The technology described above is currently being implemented and improved upon in the continuing process of the Human Genome Project. Though the current focus of the project remains the mapping and sequencing of the human genome, efforts have been and will continue to be made in the application of the findings to human biology and medicine. In the next century, after the sequencing and mapping have been mostly completed, the focus of the project will shift to the interactions and effects of all the elucidated genes. Once understood, genetic manipulation could be used in an effort to alleviate diseases and "handicaps". Before the preceding capabilities become reality, we must investigate the ethical implications of information that will be produced. Who owns the information produced and who has the right to see the results of any tests that an individual has done? What genetic engineering prospects are possible? Are the claims of eugenics and the development of a genetic underclass justified? Within each of these questions lie other questions that must likewise be answered. Hopefully, humankind will use common sense and logic rather than irrational fear in answering the challenges ahead.

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Chapter Three: Knowledge Before the Fact

"Ethical questions should be viewed in the light of the general objective of these procedures, which is to help people to live long and healthy lives and reproduce as normally and as responsibly as possible."
-H. Nakajima-

The screening of embryos and fetuses is nothing new. Such tests have been conducted since the 1960's with the advent of amniocentesis. The process of amniocentesis involves the removal of amniotic fluid from the amniotic cavity in the womb by means of a long needle. Embryonic cells are then removed from the fluid, cloned and screened for various genetic markers. Currently up to 200 disorders can be detected. The estimated risk to the mother or fetus from the procedure runs anywhere from 0.5 percent to 1.5 percent.

One of the main problems with amniocentesis is that only 15 percent of the screenable diseases are treatable.[1] A couple has only two choices. They may continue the pregnancy to term or abort. The problem with abortion is that for the tests to be run the fetus must be from 16 to 20 weeks gestated. Therefore, if a couple wishes to terminate a pregnancy due to the results of the tests, the abortion is pushed into the second trimester. This further complicates the decision process, at least medically.

A new technique called chorionic villus sampling (CVS) relieves some of the dilemma. CVS involves the snipping of material from the fetal sac with the help of ultrasound imaging. Unlike amniocentesis, this new process can provide results within nine weeks of gestation. But again, there remain only two choices: continue or abort. In addition, the safety and accuracy of the CVS test remains in question.

Several circumstances further compound the problem that couples undergoing prenatal genetic screening face. Currently, there exist only 1,000 genetic counselors in the United States.[2] This leaves much to the family doctor who may be unqualified to give such counseling and lack the time necessary to fully explain the results and go over the options. The time most genetic counselors spend with patients is lengthy and many family doctors do not have that luxury. Additionally, a couple's knowledge of the disease in question may be fuzzy. Disorders such as Down's syndrome, cystic fibrosis, Huntington's disease and other long-range or late onset disorders are not widely understood by the public. Consequently, many couples may be making a decision based upon an incomplete understanding of the proximate disease. Furthermore, the odds of a given condition developing may be misunderstood. One study showed that one quarter of middle-class pregnant women believed that a chance of one in 1,000 translated to a 10 percent probability.[3]

Despite these controversies, interest in prenatal-natal genetic screening has increased both in the public sphere and in the research laboratory. In 1970, only 200 fetuses were genetically screened. By the early 1990's, only 20 years later, more than 300,000 embryos were screened per year. The first International conference on Prenatal-Implantation Genetics in Chicago drew 250 researchers.[4] Prenatal-natal genetic screening appears here to stay. The information provided from the Human Genome Project merely promises to expand the number of "disorders" that can be screened.

New fertilization technology appears to sidestep many difficult questions raised by amniocentesis and CVS at first glance. In March of 1992 at Hammersmith Hospital, a baby by the name of Chloe O'Brien was born. Unlike most babies, Chloe arose through the implantation of a zygote into her mother following conception in vitro. Chloe was in other words a "test-tube baby". Though the first in vitro fertilized (IVF) baby was born in 1978, Chloe was special because she had been genetically screened for cystic fibrosis before implantation.[5]

This process of combining in vitro fertilization with genetic screening eliminates the main dilemma raised by amniocentesis or CVS. Prenatal-implantation screening of IVF embryos provides more options than amniocentesis or CVS. Many ova from a woman may be fertilized with sperm and the eventual zygotes genetically screened. Only those zygotes with acceptable genetics need be implanted. This process eliminates the need for an abortion to prevent the birth of a child with detrimental defects. Unfortunately, there remains the problem of what to do with the unfit zygotes. A consensus has yet to be reached about this. Researchers at Howard and Georgeanna Jones Institute for Reproductive Medicine in Norfolk, Virginia hope to begin the first embryo screening program in the United States. Initially, the test would screen for Tay-Sachs disease, a fatal disorder found prominently in Jews of Eastern Europe descent.[6] Additionally, the Genetics and IVF Institute in Virginia plans to begin testing IVF embryos for several disorders including cystic fibrosis and sickle-cell anemia, diseases primarily afflicting people of African descent.[7]

Several objections may still be raised against the prenatal-implantation screening of IVF embryos. Due to differing views of the embryo, some people may object to the disposal of unfit embryos as some have already objected to IVF itself. This process may also lead to the gene therapy of germ-line cells which raises its own ethical questions (discussed later in chapter five. Finally, there remain the continuous questions about the manipulation of nature. Some charge that these new techniques usurp the bounds of what is natural. As in other cases, such as transplantations, research scientists and medical professionals appear to be "playing God".

These objections aside, the use of pre-implantation genetic diagnosis and the nontransfer of embryos appear ethical to many people. It allows for the birth of healthy babies free of genetic defects while avoiding abortion. The only concern of an ethical nature in this process is the status of the unused embryos. However, such embryos exist at such an early stage of development that they lack any sensation beyond that at the cellular level. Thus, many people refuse to confer any rights, interests, or obligations to them. Nevertheless, the nontransfer of an embryo is far more acceptable than the abortion of a fetus.[8]

Pre-implantation screening does not, however, eliminate the underlying question behind all prenatal genetic diagnosis, that of eugenics. Eugenics is not the necessary outcome of prenatal genetic diagnosis, but it remains a possibility. Without regulations, abuses of this new technology appear inevitable. If one considers prenatal sex-selection an abuse, recent trends are at the very least

disturbing. Both among the lay person and the professional there exist support for eugenics. The Massachusetts General Hospital in Boston reported over 1,000 inquiries about CVS for sex selection in a single year.[9] A national survey of geneticists showed an increase in the approval of genetic screening for sex selection from 1 percent in 1973 to 20 percent in 1988.[10] In India, government reports estimate that between 1978 and 1982, 7,999 out of every 8,000 or about 99.9 percent of all abortions in Bombay involved female fetuses. Furthermore, 62 percent of 295 US doctors surveyed said they would either perform the diagnosis or refer couples to a physician who would, if the couple insisted upon genetic screening for sex selection. Internationally the percentages are a little less: United Kingdom-24%, Greece-29%, Brazil-30%, Israel-33%, Sweden-38%, Canada-47%, and Hungary-60%.[11] Thus, especially in the US, physicians are willing to perform tests exclusively for sex selection.

This seemingly widespread acceptance of sex selection lends considerable support for the claims and worries of eugenics and screening for "undesirables" such as: low I.Q., short stature, or poor eyesight. Additionally, the NIH announced a grant of $600,000 to track the genes for I.Q. in order to find "the really smart kids".[12] Furthermore, a poll of New England couples found that 1 percent would abort a fetus based upon sex, 6 percent would abort a fetus with the likelihood of developing Alzheimer's, and 11 percent would abort a fetus predisposed to obesity.[13] Dr. Francis Collins, the geneticist who helped identify and isolate the gene for cystic fibrosis, states, "I see people occasionally in my clinic who have a sort of new

car mentality. [The baby's] got to be perfect, and if it isn't, you take it back to the lot and get a new one." "We do have in our society a premium baby mentality," adds Mary Mahowald, professor at the Department of Obstetrics and Gynecology at the University of Chicago.[14] To make matters worse, Dr. Lawrence D. Platt, geneticist at the University of Southern California, points out that requests for genetic tests by doctors remain "much higher than ethnic [groups where the disease is frequently found] requests. Once there is public awareness about the technology, other people will use the procedure as well."[15] Currently, most of those people requesting tests are physicians, who are informed about such tests. Once the public becomes better informed requests could rise drastically, at least among the wealthy.

Support for these claims may be found in the prevailing attitudes of many people, especially those who can afford such procedures. Many parents go to great lengths to make sure that their child has every advantage possible. Whether it means sending their child to a private school or camp or giving them growth hormone supplements, many parents want their child to be ahead of the game at all costs. With the emphasis that our society seems to put on success and winning, it is no wonder children are taking private lessons and steroids. Why not start with the building block from which everyone is made, their DNA? As George Annas notes "the whole definition of normal could well be changed, the issue becoming not the ability of the child to be happy but rather our ability to be happy with the child."[16] These procedures allow us to give our children the ultimate head start.

Under the social pressure of success, these techniques could lead anywhere.

Devoid of regulation, practices could spiral out of control. With the current health care system in the United States and the great disparity in wealth, it would not take long for the development of a genetic underclass. The wealthy, able to pay for the extravagant costs of genetic diagnosis, could guarantee "desirable" offspring free of genetic "defects". The poor, unable to pay the costs of such tests, would continue to play Russian roulette like most of us do today. Ultimately, there could be two classes of individuals--the genetically fit, and the genetically unfit--further widening the disparity between the haves and the have-nots. "The new commercial eugenics of birth is every bit as frightening as the political eugenics of the past, only it will be far more difficult to identify and control."[17]

Ideally, traditions and standards of morality would guide us in making decisions about how best to use these techniques. Nevertheless, in the face of a multicultural society and with at least its apparent ethical relativity and a certain hedonism, appeals to tradition and standards may not be enough. Additionally, the pace at which these tests are being developed far exceeds the ethical determinations our moral discussions form on such matters. The economic incentive for physicians and companies to push such tests may be irresistible. To cope with such problems, governmental legislation or some internal guidelines should be enacted. For example, in response to the sex selection through abortion, the India government passed a law criminalizing the disclosure of a fetus's gender in 1988. Furthermore, the following guidelines were suggested by James Wyngaarden:

1) The limitation of genetic diagnosis to serious conditions.
2) The use of only those diagnostic tests that are accurate.
3) The limitation of genetic diagnosis to those disorders with therapy or intervention available.
4) The development of economically reasonable screening processes.

Although these guidelines could serve as a start, they should be elaborated and amended. For example, there is no inherent reason to limit prenatal genetic screening to treatable diseases. In fact, the prenatal genetic screening of untreatable diseases may be the best course of action. Nevertheless, such legislation and/or guidelines are needed to protect doctors who currently find themselves in a legal limbo. Without any regulations, doctors may become subject to lawsuits for not recommending tests or procedures. As of 1990, over 300 cases had been filed in approximately a dozen states by parents or children claiming "wrongful life" or "wrongful birth".[18]

The Human Genome Project promises us great information, useful information that can be used for the betterment of humankind. However, the information can also be misused, misunderstood, and misinterpreted. The problems that are currently created by prenatal diagnosis will only be compounded by this information. If guidelines are not set up, then the possibility of widespread abuse appears inevitable.

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Chapter Four: Knowledge Without Treatment

"It's not a good test if you can't offer people treatment. . . .Knowledge alone doesn't provide the support you need to live your life, you need to know there's hope."
-Nancy Wexler-[1]

The Human Genome Project promises to unwrap the entire human genome. In the short term, we will gain knowledge of the genetic component of man in the same way we have come to understand the human skeleton. Ultimately, the genetic framework may be used to find chemical and mechanical tools capable of changing the genetic structure itself. Just as we can replace limbs and joints with increasing success, we may one day be able to accurately replace genes much of society considers defective in some way. Until that day arrives however, we can screen individuals for a growing number of diseases. Often this screening can predict future problems years before any symptoms appear. This would give individuals the knowledge to begin curative treatment programs early before the onset of disease. Unfortunately, such treatment is not always available.

More than four thousand diseases are believed to be of genetic origin including sickle-cell anemia, hypertension, diabetes, some cancers, Huntington's chorea, muscular dystrophy, cystic fibrosis, Alzheimer's, alcoholism, polyposis, and Down syndrome.[2] Additionally, even manic depression, schizophrenia, and a predisposition to such illness as heart attacks, arthritis, allergy, and learning disabilities may have a genetic origin. Approximately a thousand disorders have been identified. Of these, only a select few have any type of therapy or treatment

currently available. The remaining disorders can only be prevented to varying degrees. Though genetic diagnostic tests have not been developed for all of these identified disorders, hopes remain high that tests will one day be available. In 1984, Ray White, from the University of Massachusetts medical school, stated that "we will soon be in a position to reduce the toll of human genetic disease."[3]

Unfortunately, these diagnostic tests and the information they generate carry with them a heavy load of questions and concerns. White writes in an article for The Lancet:

> Intriguing questions are beginning to emerge as we contemplate other applications of knowledge of individual genotypes. Is it ethical or even useful to reveal the future when no therapy exists? Insurance companies will want to know of people at increased risk genetically of heart disease. Should they be allowed access to such information? Will there be a statutory requirement for a man and a woman to share genetic information before they marry and could failure to disclose genotype become grounds for divorce? Will 'my genotype made me do it' become an acceptable defense in criminal cases?[4]

In a little known report by the American Council of Life Insurance in June 1989, similar sentiments were expressed. "As genetic testing is perfected, society will be forced to confront important issues that have never before been of such widespread concern. Profound ethical questions will be posed concerning the practice of medicine, procreation, employment, privacy, individual versus social rights, confidentiality, 'the right to know' and the 'right not to know.'"[5] Instead of keeping this matter among those with interests at stake, the public needs to be involved and informed.

These questions remain important and unanswered. Though the technology does not yet exist for wide scale screening of many diseases, such technology will

soon be available. Neil A. Holtzman, a geneticist at John Hopkins, estimates that 2.4 million women will be undergoing prenatal tests per year in the future. Another 2.8 million women a year will undergo screening to see if they are carriers of the four major genetic disorders: cystic fibrosis (750,000), sickle cell anemia (152,000), hemophilia (940,000), and muscular dystrophy (940,000). Additionally, he predicts that 16.2 million people will undergo genetic diagnosis for predisposition to various diseases. [6] Philip Reilly, a physician and lawyer specializing in bioethics, provides further support, saying:

> It's inevitable that carrier testing is going to happen and when that happens we'll be testing millions of people. What this means is that we better get a handle on what kind of information we'll be producing, who will use it, and keep it from being mishandled, misunderstood, or poorly protected. And while some people still say we have time to deal with the broader issues beyond cystic fibrosis, scientists who see how quickly advances are coming know we ought to begin thinking about this now.[7]

As Hayden and his colleagues noted in 1989, "these issues must be addressed before this type of testing becomes widespread. In our experience, predictive testing is far more complex than had been anticipated."[8] We may not foresee all the issues arising from genetic diagnosis but we must answer those questions we do expect. The time to answer these and other questions is now, before every person's genotype is known from a simple blood sample. Genetic screening and monitoring could very easily make genetic privacy and related issues the central civil rights focus of the next century.

One of the first diseases to have a genetic test available was Huntington's disease. A prominent figure involved with the problems of Huntington's disease and

the new test has been Nancy Wexler. Wexler has not only worked in tracking instances of the disease in families but also stands a fifty percent chance of developing the disease herself. When she was first told about the discovery of the gene for Huntington's disease back in the spring of 1983, she "danced with surprise and joy."[9] A test for screening purposes would soon be developed along with this discovery. With this test, people could learn years, possibly decades, before the onset of any symptoms if they were going to develop this disease. Additionally, the hope of therapy for the disease being developed increased. At last, many people could find relief from a "terribly burdensome anxiety, fear, and worry" when they were told they had not inherited the gene. On the other hand, those that learned they had inherited the gene "might be hurt in ways impossible to gauge."[10] Wexler notes:

> Instead of worrying if they have the disease, people who are told they have the gene now worry when they will get it. The test still provides some people great freedom, but it also can be very destructive. People have spent their lives shielding themselves against the disease. Bad news will break that shield apart and what will they replace it with? Knowledge alone doesn't provide the support you need to live your life, you need to know there's hope.[11]

Boston University geneticist and psychologist Richard Myers echo Wexler's fears saying, "It's a dangerous test."[12] Realizing these potential "landmines", Wexler fought to slow the development of a widespread testing program. "In conversations with researchers and doctors, she [Wexler] argued that special counseling programs must first be put into place before anyone was given the test."[13]

Six years after the discovery of the Huntington's disease gene no real

progress had been made in providing treatment though it remained possible to be tested. In an interview in Columbia, a Columbia University publication, Wexler noted:

> When it first became available, my sister, father, and I had no question about taking it. My sister and I thought, 'Isn't this fantastic! We could have children! My father could stop saving money for nursing homes and retire.' When we thought more about it, however, my father was first to say, 'Wait a minute! I don't want to know if either of you has a bad outcome. One bad outcome and we're all three dead.' Both my sister and I would have to have a good outcome for all of us to be free.[14]

Without any form of treatment, the test shatters any hope that a person or family may have before testing positive. Because of this, many people would rather live a life of uncertainty. Wexler says, "Confidentiality is a big issue, even within families, sometimes between brothers and sisters, because some people want to know and others don't."[15] This issue of wanting to know or not know becomes even more complicated when identical twins are involved since both have the same genetic composition.

Other problems arise from insurance companies and employers. "There are problems we never could have predicted," Wexler explains. "We hear that insurance may be denied to people who know they have the gene."[16] Insurance companies already charge higher rates to or reject altogether those individuals at risk of developing Huntington's disease. In a study by E. Virginia Laphom of Georgetown University and others, 22 percent of 332 persons having history of genetic illness in their family reported being denied health insurance.[17] If an individual knows for sure they will develop the disease insurance companies will be

sure to deny these individuals or charge them an inflated premium. Because of such problems, only about 200 of the 125,000 people in the United States at risk of developing Huntington's disease have been tested.[18] Special attention should be paid to the Huntington's disease test because of the fact that it is the first genetic test of its kind. Thus, this test will set the precedent for other tests that follow. As Hayden believes and others agree, the Huntington test "will eventually serve as a model for similar programs for other late-onset genetic diseases"[19] such as heart disease, cancer, mental health illness, and Alzheimer's.

Discrimination against persons knowing their genetic defects has become of concern to many. The sources of discrimination are varied, but primarily they are employers and insurance companies. Dr. Paul Billings, from the division of genetic medicine at California Pacific Medical Center, and others have found several cases of genetic discrimination. People have been refused a job or insurance based solely upon "poor" genetic printouts. Because of such cases, Wisconsin became the first state to forbid discrimination based on genetic diagnosis for employment or insurance purposes in 1992.[20] More specifically, Reilly states:

> There is plenty of reason to believe that carriers [cystic fibrosis], if identified, will be stigmatized, by their employers or insurance carriers, as being sick or as being at risk of getting sick even though that's preposterous. There's concern that even many doctors don't really know what it means to be a cystic fibrosis carrier. The technology has gotten way ahead of us.[21]

Once again, we can see the problems caused by misunderstanding the data and what the data means. For example, being a carrier for a disease simply means that one out of two alleles for a given gene is defective not that the person will develop

a disease. Usually, such an individual can live a completely normal life without even knowing they are a carrier. In such cases, problems only arise when two carriers get married and have children. Testing can enlighten couples to their chances of giving birth to a "defective" child.

This problem need not wait until the Human Genome Project has finished elucidating the human genome.

> Even before the complete genomic map is drawn, the broad outlines of a personal genetic profile could be constructed based on those genes already mapped and identified. By use of a simple blood test, it will be possible to see an individual's private constellation of known genes, and, thereby, reveal the biological foundation upon which is built a person's particular health, personality, and physical and mental talents.[22]

And when such a profile is known the threat of discrimination from all arenas arises. Marc Lappe, of the University of California School of Public Health in Berkeley, explains:

> When we can know that a person is at risk for a major disabling or costly condition long before he or she manifests symptoms, does society have a right to invoke prepayment, taxation, or other schemes to offset the inevitable cost of the disease? The obvious rejoinder is that such a scheme is regressive, and has a disproportionate and hence coercive impact on the poor. But this ignores the overwhelming social reality that we are reaching a point where virtually no one can afford to pay for the long term care of chronically diseased individuals. The social reality threatens to drive medicine away from its largely humanitarian base, and toward the use of predictive tests that allow cost savings no matter how discriminatory or prejudicial the process.[23]

Possibly more important, if such a scheme is activated, then the question becomes, At what level of risk does the scheme take effect? Here we see the perspective taken by utilitarianism, as developed by Jeremy Benthem and later John Stuart Mill. According to this philosophy, an act is judged moral or immoral based on the

principle of the greatest utility, the greatest happiness for the greatest number. The calculus of felicity developed by Benthem is useful in deciding what action to take. Here, the question would be, What general rule will allow for the greatest benefit of society? Thus, utilitarianism supports communitarianism (the good of the society over the good of the individual).

Genetic screening for employment purposes is really an old topic. The arrival of the Human Genome Project merely enlarges the scope and breadth of the issue by promising to add to the growing number of diagnostic tests. As early as the 1960's, the United States Air Force screened Afro-Americans for the sickle-cell gene, because of the higher frequency of the gene in this segment of the population. Claiming that such a test was necessary to prevent possible complications due to low oxygen content at high altitudes, the Air Force Academy banned Afro-Americans testing positively for the sickle-cell gene from entering for nearly a decade. Finally, in 1981, they relinquished their ban under pressure from lawsuits as no scientific evidence existed to support their claim. Additionally, it should be noted that others have likewise screened for sickle-cell gene only in Afro-Americans even though the gene may appear in all segments of the populations.[24] Thus, we see evidence for the "scientific" discrimination of minorities.

More recently, the incident of genetic screening for purposes of employment was reported by the Congressional Office of Technology Assessment (OTA) in 1990. In their report, the OTA found that 13 percent of the Fortune 500 companies have or are utilizing some form of genetic screening or monitoring for workers.

Furthermore, about 20 percent of companies think they might use DNA screening of workers within the next five years.[25] Thus, the next time you apply for a job you may be required to give a blood sample for genetic testing in addition to the urine sample for drug testing. The privacy of the individual may increasingly diminish. Ultimately, we could end up with what Dorothy Nelkin, a sociologist at New York University, and Laurence Tancredi, director of the health law program at the University of Texas Health Science Center in Houston, refer to as a new class of unemployables. They write:

> Could not genetic diagnosis techniques create a growing class of unemployables, not on the basis of existing symptoms but on the anticipation of possible future symptoms. In a competitive economic environment, industry must try to select the `best' employees on the basis of both potential productivity and future health. If future medical risk becomes a criterion, individuals could find themselves on genetic blacklists, classified as unfit for work.[26]

Our fate may become more dependent upon our genetic map than our character. This emphasis on intrinsic properties, like genes, goes contrary to the teachings of philosophers and Judeo-Christian beliefs which stress the importance of the character. At a time when our society is attempting to reconcile the deeds of past racial discrimination, this new technology threatens to open new avenues of genetic discrimination. People may one day find themselves blacklisted by employers or insurance companies due to their genetic constellation. Others may simply find themselves ostracized by society.

There also arises the question of whether a company should improve the working conditions to eliminate the need for worker risk assessment or simply ban

people with a genetic predisposition to environment-specific illnesses related to working conditions. A recent congressional report notes:

> Genetic information may be used by employers through genetic screening or genetic monitoring programs. . . .Individuals may be screened for genetic traits that render them susceptible to a pathological effect if exposed to special agents present in the workplace. . . .Individuals also could be screened to detect general inherited characteristics not necessarily associated with occupational illness. Genetic information may be used to screen applicants for employment or current employees. . . .Once acquired the data may also be used to make decisions about the careers of employees. . . .Misuse of genetic information in employment, insurance and other areas is likely to involve some type of unfairness and discrimination.[27]

According to Lappe:

> The ethical issue here centers on what governments and employers will do once they know someone ought not work in a dusty or smoky factory. If what they choose is to ban the person, then we have a serious problem of genetic-based discrimination. A more enlightened but understandably more expensive approach would be to clean up the factory.[28]

This is an important issue as 400,000 employees contract disabling occupational illnesses (blood disorders, cancers) and 100,000 die due to hazardous job environments yearly.[29] What responsibility do employers have to screen employees? Should employers be allowed to screen employees rather than improve conditions? Should companies be held liable for illness afflicting an individual not tested for genetic predisposition? Judeo-Christian ethics support the view that each of us is our brother's keeper. Also, employers have taken a greater interest in the health of their employees recently, suggesting that they would want to improve conditions and screen out individuals at higher than normal risks. Legally, it seems likely that companies could be held responsible for not screening

or improving work conditions. But, which should they do? These questions remain unanswered.

The other arena of discrimination is insurance. Many insurance companies will cover the cost of genetic testing, which for Huntington's disease runs $3,000 at Boston University, but only if they get access to the results.[30] Myers describes the problem saying:

> The fear, and it's legitimate, is that the insurers will limit coverage or drop them completely if it turns out they have the gene. It's a terrible situation because the person with the gene will need the protection of insurance even more, not less. . . . People ask me what they should write on an employment or insurance application when it asks them it they have a health problem; should they write they have this gene that will cause a problem in 10 or 20 years? I'm still not sure what advice to give. But I'm sure my explanation, that they may jeopardize their insurance is why a lot of people aren't taking the test.[31]

The problem is complex with no real answer in sight. Many people will forego predictive testing that could lead to preventive medicine for fear of being discriminated against by their insurance companies.

The insurance companies do have a point. The current insurance system in the United States is based on calculated risk. If genetic testing results are withheld from insurance companies the true risk that an individual possesses remains hidden. As one insurer put it, "Is it fair for someone who knows they are going to die prematurely to load up on a million dollars in life insurance?"[32] Myer admits:

> I didn't like what the people at the company said, but they had a point. You know, we felt people would have all sorts of reasons for not taking the test. They might not want to know, maybe people in their family who had to provide blood for analysis wouldn't be helpful, or were unreachable. But the insurance thing isn't something we expected or were prepared for. Yet, it's become the greatest barrier to testing we know of. People feel very scared

about letting this information loose. They're worried who will get hold of it.[33]

The report by the American Council of Life Insurance notes:

> If insurers were unable to use genetic results during the underwriting process because 'risks should only be classified on the basis of factors that people can control,' then equity would give way to equality (equal premiums regardless of risk) and private insurance as it is known today might well cease to exist. . . .As technology is perfected and/or genetic testing within the general population becomes common, insurers may eventually consider ordering genetic tests.[34]

If such tests are ordered and increasing numbers of people find themselves uninsured, the federally funded portion of the health care system will see an increased amount of strain. Such events, affecting persons of all classes, may even push the nation to change the way the health care system is organized. This may not necessarily be a bad thing, but we should investigate the situation to better guide the future of insurance coverage.

The issue of genetic screening has two sides. While there appear to be many advantages to providing genetic screening, many unforeseen obstacles and problems have arisen. Besides the larger societal issues surrounding discrimination and privacy, there are more individual and personal issues. "People found to have genetic lesions will be able to choose how and whether to have children, but many will also have to live with the knowledge (if they choose to obtain it) that illness awaits them and that medicine may have little to offer."[35] Lappe cautions that genetic screening "can set in motion a sequence of personal reassessments that leads to feelings of reduced self-worth and autonomy."[36] Although genetic screening tests may relieve anxiety or provide the information needed to make

informed decisions about lifestyle, life plans, and children, the ELSI warns that "if misinterpreted or misused, these new tools could open doors to psychological anguish, stigmatization and discrimination."[37]

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Chapter Five: Engineering Ourselves and the Future

"What people lose sight of is that genetic engineering is about engineering--taking the principles of technology and applying them directly to the genetic code of microbes, plants, animals and humans. . . .It involves the application of the criteria of utility and efficiency to all these life forms. The potential benefits are marvelous--but in the end the philosophical assault on our concept of life is at least as impressive."
-Jeremy Rifkin-

Gene therapy, often referred to as genetic engineering or gene transplantation, has been defined by Dr. W. French Anderson, leading NIH investigator in gene therapy, as "the insertion into an organism of a normal gene which then corrects a genetic defect."[1] There are two different forms of gene therapy, somatic and germ line. Somatic gene therapy deals with the correction of genetic defects in somatic cells, which are not passed on to offspring. Germ line gene therapy concerns itself with the alteration of genetic malformations in germ line cells, which may be passed on to offspring. Because of this difference between germ line and somatic cell therapy, germ line therapy raises many more ethical concerns. Before these problems can be examined, the techniques involved should be understood.

The three major techniques that can be envisioned in gene therapy include: gene insertion, gene modification, and gene surgery. The first, and only, strategy that currently exists is gene insertion. This procedure involves the simple insertion of one or more copies of the normal version of a gene into the genome of an individual. Most frequently, viral vectors are used to introduce bits of DNA that must be picked up, incorporated, and finally properly expressed by the targeted cells.

One of the newest and more experimental instruments used in gene insertion is the Biolistic PDS-1000/He. This "gun" uses high velocity microprojectiles or microcarriers coated with foreign DNA or other macromolecules. These mircoprojectiles are used to introduce the foreign matter into a wide range of living tissues, cells, and organelles. This process is nondiscriminatory and extremely versatile. Unfortunately, in December 1995, an NIH review announced that "clinical efficacy has not been definitively demonstrated at this time in any gene therapy protocol."[2] The second technique is gene modification. Gene modification would involve the chemical modification of the defective DNA sequence so that it reads properly. This procedure would be done on intact living cells. Such a technique would be less likely to disrupt the geographical layout of the genome which would cause drastic and unwanted side effects. The third and most ideal strategy would involve the exact replacement of the defective gene with a good copy of the gene. This technique, gene surgery, would require the removal of the defective gene precisely with the subsequent replacement of freshly synthesized normal gene. Gene surgery remains far beyond the reach of modern abilities and comprehension of the human genome and genetics.[3]

Genetic engineering, whether for correction or enhancement, carries with it many risks and problems that have yet to be fully considered. The new or corrected gene must be expressed without disrupting other metabolic processes. The gene must also stay integrated and intact upon subsequent cell division. Our current technology of gene insertion does not allow for the precise insertion of genes.

Thus, a gene could inadvertently be introduced into the middle of a normally functioning gene disrupting its processes. Such an event would only further complicate the problem. The quantity of the gene, the number of copies, integrated into the cell also remains uncertain. Present technology only allows for random integration of genes. The new gene often inserted with the help of retroviruses could activate silent protooncogenes causing cancer to develop. Besides the scientific and practical problems associated with this type of therapy, there remain a plethora of unanswered ethical problems associated with both somatic and germ line gene therapy. Somatic cell therapy, in alleviating genetic defects in somatic cells, only affects the individual undergoing treatment. On the other hand, germ line cell therapy has far reaching effects on future generations of human beings by altering the genetic composition of germ cells. In general, early critics worried that this new technology would result in the treatment of life forms, especially human beings, as machines, whose "defective" parts could be engineered or replaced. Another problem is the vagueness associated with "defective" genes. What exactly does defective mean? As Evan Kemp, commissioner for the Equal Employment Opportunity Commission (EEOC) and a disabled person as well, states:

> The terror and risk that genetic engineering holds for those of us with disabilities are well grounded in recent events. Our society seems to have an aversion to those who are physically and mentally different. Genetic engineering could lead to the elimination of the rich diversity in our peoples. It is a real and frightening threat.[4]

And what type of "defect" is serious enough to warrant the risks associated with the procedure? Additionally, there is the possibility of moving from correcting problems

to enhancing "normal" characteristics, or gene enhancement. In 1967, the Nobelist who first described the "language" of DNA, Marchall Nirenberg, projected:

> That cells will be programmed with synthetic messages within 25 years. . . .The point that deserves special emphasis is that man may be able to program his own cells long before he will be able to assess adequately the long-term consequences of such alterations, long before he will be able to formulate goals, and long before he can resolve the ethical and moral problems which will be raised.[5]

Though Nirenberg overestimated the abilities of human technological advancement, the questions surrounding gene therapy remain unanswered.

More than a dozen somatic cell gene engineering experiments exist throughout three continents.[6] Unfortunately, as with experiments involving the artificial heart and xenograft transplants done in the 1980s, early research is being done on those with little choice. Children, unable to fully consent, and the terminally ill, easily persuaded, continue to be the guinea pigs for such experiments.[7] Some believe that such experiments should not be performed at all because "somatic cell enhancement engineering. . . .would be morally precarious."[8] They raise the questions: what genes will be targeted, who will get access to gene therapy technology, and what preventions are there against discrimination of those who do or do not undergo therapy?

Another concern "is that it [gene therapy] will inevitably lead to the insertion of genes to change the character of people, reduce the human species to a technologically designed product, or even 'change the meaning of being human'."[9] Though this concern may seem unjustified, much contemporary sociological

phenomena supports this idea. Our society appears obsessed with perfection. Television and advertisements constantly bombard us with images of the "perfect" baby. Presently, exercise and diets are the main ways for achieving perfection, but cosmetic surgery and liposuction are also used. A quarter of a million Americans have undergone liposuction. Kimbrell points out that in 1990 alone, Americans spent $33 billion on diets and diet-related services with such expenditures expected to be near $77 billion by the year 2000. Kimbrell further notes that muscle-building equipment accounts for $750 million while numerous infommercials and exercise tapes are available for our convenience. "More is spent on fitness and cosmetics in the United States than on education or social services," declares Kimbrell. Furthermore, Kimbrell notes other evidence showing the vanity of America. Polls indicate that over the past 15 years the number of men unsatisfied with their body doubled to 34 percent while for women it doubled to 38 percent. Of these, over 50 percent were unhappy with their weight or abdomen size. Surveys also show that a large number of Americans are deeply concerned with height, muscle tone, and facial characteristics. One and a half million Americans have undergone "aesthetic" surgery. Every year the cosmetic industry takes $4 billion out of our pockets. [10] Gene therapy provides a new and easier means of achieving these dreams. Our obsession with perfection does not stop with the body, however. The California based Repository for Germinal Choice, or the Nobel Prize sperm bank, is home to the sperm of men with renowned scientific, athletic, or entrepreneurial ability. The sperm is expressly used to create genetically superior offspring from women of high

intelligence.[11] This is an idea similar to that found in the movie Twins.

Despite these ethical questions concerning gene enhancement, many still believe that somatic gene therapy for the correction of serious illnesses is ethically justified. Dr. Anderson is one such supporter, explaining that "somatic cell gene therapy for the treatment of severe disease is considered ethical because it can be supported by the fundamental moral principle of beneficence: it would relieve human suffering." The public also seems to largely approve as is shown by an Office of Technology Assessment survey indicating that 83 percent of the public approves of cell manipulation to cure ordinarily fatal genetic disease.[12] Furthermore, both the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and the European Medical Research Councils concluded that "somatic cell gene therapy is not fundamentally different from other therapeutic procedures such as organ transplantation or blood transfusion."[13]

As in the introduction of any new drug, procedure, or operation, certain criteria should be set up before it's used in humans. Here the criteria include: the ability of the new gene to stay within the target cell long enough to be effective, the new gene's ability to be expressed at the right level, and that the new genes not harm the cell or the host. Dr. Anderson goes so far as to suggest that with the development of such guidelines we would have a duty to perform gene therapy on humans and to do so fast.

It would be unethical to delay human trials. . . .Patients with serious genetic

> disease have little other hope at present for alleviation of their medical problems. Arguments that genetic engineering might someday be misused do not justify the needless perpetuation of human suffering that would result from unethical delay in the clinical application of this potentially powerful therapeutic procedure. . . .What's the rush? The rush is the daily necessity to help sick people. Their (our) illness will not wait for a more convenient time.[14]

Overall, the consensus seems to be that somatic gene therapy used in the correction of genetic defects is morally and ethically permissible if not obligatory. On the other hand, somatic gene enhancement remains morally problematic, especially with the imprecise technique of gene insertion.

Germ line gene therapy is treated separately from somatic cell gene therapy because germ line gene therapy has greater societal impact than somatic cell gene therapy. Changes made to somatic cells remain confined to that generation, whereas the effects of germ line gene therapy will last indefinitely. Germ line gene therapy continues to be perpetuated in the descendants of the patient long after the patient passes away. Thus, germ line genetic therapy changes the total gene pool whereas somatic gene therapy does not. As Alfred Sherwood Romer writes in The Vertebrate Body:

> Biologists have often emphasized the fact that in general the germ cells form an exceedingly independent tissue; the rest of the body, the "soma", is, in this point of view, merely a temporary structure shielding and conserving the potentially immortal gene plasma.[15]

Alexander Capron adds support saying:

> The major reasons for drawing a line between somatic-cell and germ-line therapy interventions. . . .are that germ-line changes not only run the risk of perpetuating any errors made into future generations of nonconsenting "subjects" but also go beyond ordinary medicine and interfere with evolution.

> Again, it must be admitted that all of medicine obstructs evolution. But that is inadvertent, whereas with human germ-line genetic engineering, the interference is intentional.[16]

Capron uses the principle of double effect here to show the distinction between traditional medicine and these new technologies of genetic engineering. The principle holds that an action can have two effects, one intended and the other unintended. The action is moral if the intended effect is just. Thus, whereas in most of medicine the secondary effect obstructs evolution, in germ-line genetic engineering the primary effect is to obstruct evolution. Most of medicine, including somatic gene therapy, attempts to alleviate or mend physical anomalies. The subsequent obstruction of evolution through the prolonging of a life and possibly allowing for propagation is a side effect. Obstruction of evolution stands as the primary objective in germ-line gene therapy. Unlike other medical practices, germ-line genetic engineering directly interferes with the natural progress of evolution. Because of this difference, there has been much criticism against germ-line gene therapy by propagating any changes in the genes of future generations.

Claims of eugenics are also more prevalent here than in almost any other issue regarding the Human Genome Project because of the long-term effects of genetically engineering germ cells. A resolution signed by 56 religious leaders, including Protestant, Roman Catholic and Jewish leaders, as well as eight scientists and ethicists in the Congressional Record June 10, 1983 provide evidence for such sentiment. The resolution states that ". . .efforts to engineer specific genetic traits into the germ line of the human species should not be attempted."[17] Capron will not

go this far. Rather, Capron says that purposely altering "humankind's genetic inheritance is not a sufficient reason to foreswear the technique forever, though it is reason enough to distinguish it from somatic-cell interventions."[18] Capron does not say that we should use germ-line genetic engineering technology, only that we need to look at it separately.

Three categories of arguments against human germ line genetic therapy may be found in Gene Mapping by Annas and Elias. The first group of arguments concerns itselves with probable clinical risks involved with current and future techniques. Methods capable of safely and stably integrating new DNA are needed. These concerns center on the possible: disruption of normal gene functions, activation of protooncogenes, or adverse effects of defective regulatory signals on the new gene. Problems also surround the reproductive technology, like in vitro fertilization, needed to implant the genetically manipulated germ cells. Annas and Elias believe that "unless there is overwhelming evidence that the procedure will be successful and not cause harm to the resulting child, there is no justification for doing genetic experiments on an early embryo and then reimplanting it."[19] Instead of genetically engineering, prenatal screening could be done to eliminate those embryos unfit for implantation. Unless both parents were homozygous for the defect, the abnormality was undesirable, and the couple was unwilling to use outside sperm or ova, there exists no need to genetically engineer germ cells.

The second category of arguments centers on more general concerns of changing the gene pool. The gene pool is shared by all human beings and so the

removal of a gene from this pool affects everyone. "Genetic diversity, in both human and nonhuman species, is a precious planetary resource, and it is in our best interests to monitor and preserve that diversity."[20] If the genetic diversity of this pool is decreased then the human race could be ill prepared for environmental changes that occur in the future. "What may be considered a harmful genetic trait today could be neutral in the future or could even conceivably serve a beneficial function, depending on environmental pressures in which the trait operates."[21] For example, it has only recently been discovered that the cystic fibrosis gene may provide additional protection against melanoma. There is also a correlation between high levels of sickle-cell trait and resistance to malaria, suggesting a benefit in carrying the sickle-cell trait.[22] Thus, many genes that have some deleterious effects may also have unknown beneficial effects. "Hereditary information that is of value, not for the individual but for the species, maybe lost."[23] When combined with nonlethal genes, lethal genes may confer some benefits on the whole population. Yet, in contemporary society, it remains difficult to demonstrate any right humankind has to preserve the genetic diversity of the whole species while causing a future child great pain or death. This is especially true when the technology exists to establish a gamete bank to preserve the diversity of the human gene pool. Still, Robert Morison's warning rings clear:

> The nominalist biological position is that there can be no such thing as an ideal man. Men are brothers simply because they all draw their assortment of genes from a common pool. Each individual owes his survival and general well-being partly to his own limited assortment of characters and partly to the benefits received through cultural interchange with other

> individuals representing other assortments. It follows that the brothers in such a human family have a sacred obligation to maintain the richness and variety of their heritage--their human gene pool and their common culture. Every man in a sense must become his brother's keeper, but the emphasis is on keeping and expanding what both holds in common, not on converting one brother to the ideal image held by the other.[24]

It is within this group of arguments that we see the greatest clash between individual well-being and rights and the well being of the whole society. Here communitarianism, the belief in the supremacy of the state or community over the individual, runs into individual liberties.

The final grouping of arguments deals with social dangers. The problem here centers around the concern of gene therapy turning into "enhancement genetic engineering". "Adding a normal gene to correct the harmful effects of a nonfunctional or dysfunctional gene is different from inserting a gene to make more of an existing product," states Dr. Anderson. The issues here are analogous to those of athletes using steroids. Besides the fairness issue, there are many health problems that may be unknown surrounding the production of additional gene products. What characteristics will the additional gene alter? What will be the effect on the overall metabolic balance? It is this constant urge to "improve" upon nature that many condemn. As Annas and Elias put it, "The intentional alteration of germ-line genes seems to be the real reason that some condemn it as presumptuously 'playing God' and crossing a symbolic barrier beyond which medicine and mankind become involved not in treating disease, but in recreating ourselves."[25] Another voicing of this concern can be found in Dr. Anderson's statement:

> I fear that we might be like the young boy who loves to take things apart. He is bright enough to be able to disassemble a watch, and may even be bright enough to get it back together again so that it works. But what if he tries to "improve" it? . . .Attempts on his part to improve the watch will probably only harm it. We will soon be able to provide a new gene so that a given property involved in a human life would be changed--e.g., a growth hormone gene. If we were to do so simply because we could, I feel that we would be like that young boy. . .We, like him, do not really understand what makes the object we are tinkering with tick. Since we do not understand, we should avoid meddling. Medicine is still so inexact that any modification (except perhaps one which returns towards normal a defective property) might cause severe short-term or long-term problems.[26]

Society seems to constantly be looking for ways to improve. These new technologies and our constant desire for perfection could be just the combination needed to cross the fine line from treatment to enhancement.

The English mathematician, Francis Galton, coined the term "eugenics" and defined it as "the science of improving human conditions through judicious matings. . .to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable."[27] Allegations of eugenics comprise a major portion of the arguments against social dangers. "While genetic manipulation of human somatic cells may lie in the realm of personal choice, tinkering with human germ cells does not. Germ-cell therapy, without the consent of all members of society, ought to be explicitly forbidden," according to Knudtson and Suzuki.[28] Such a belief is supported by many bioethicists and governments. Annas and Elias note, "Many bioethicists believe, and existing governmental policy in the United States, Germany, and other nations maintains, that it is wrong to impose the risk of serious harm on those who cannot themselves consent."[29] More importantly, such changes

do not require social control. According to an OTA report, "New technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control."[30] Additionally, the line between eliminating a particular disease and genetic enhancement remains fuzzy. As Sheldon Krimsky points out, "Is chemical hypersensitivity a disease? Any trait that has a higher association with the onset of a disease may itself be typed as a proto-disease, such as fibrocystic breasts."[31]

Other problems that cannot be easily grouped lie more with the ideas behind the technology. For any recessive gene to be eliminated, widespread genetic screening programs would have to be enacted. Yet, evolution provides for the constant production of new disease-causing DNA sequences resulting from natural random mutations. Thus, we would be continuously trying to perfect the genetic sequence again and again. Also, "a gene that fails to perform to our satisfaction under one set of nutritional, climatic or other environmental conditions might possibly perform quite satisfactorily in another setting."[32] Another problem is that the majority of traits are the result of polygeny. Most traits result from the interaction of more than one gene. The polygenicity of a trait makes gene therapy extremely complex, difficult, and unpredictable. Finally, "we have no national or international mechanisms that will prevent germ-line engineering from permanently altering our human genome, no restrictions on the unlimited genetic alteration of sperm and eggs, or the engineering of embryos."[33]

Those who support human germ-line genetic engineering seem to support

the individual over the species. Such people believe that it is a mistake to equate eugenics and germ-line therapy. "There is no slope that leads inexorably from therapeutic germ-line interventions intended to benefit future persons to the creation of eugenically driven genocidal social policies."[34] Eugenics policies are aimed at "improving" the overall gene pool of the species whereas germ-line therapy targets the individual. "Nazi eugenic policies were not aimed at benefitting individuals. . .Public health, not individual therapy, was the driving force behind the Nazi medicalizaton of eugenics."[35] Past eugenics policies, like those of the Nazi's, intended to rid society of Nazi stipulated "bad" genes. Germ-line therapy merely hopes to prevent further people from suffering the consequences of devastating diseases. Of course, the eradication of a genetic disease would mean the loss of genes and a so-called purification of the gene pool. However, such a result is not intended. Besides, argue many, "some genetic diseases are so miserable and awful that at least some genetic intervention with the germ-line seems justifiable."[36] Somatic gene therapy corrects the problem for the time being, but the disease could show up again in the next generation from phenotypically normal heterozygous "carriers". Germ-line therapy would prevent this from happening. With germ-line therapy, only one treatment would be needed instead of repeated treatments. Germ-line therapy may also be the only type of therapy available for the treatment of some cells or tissues unamenable by somatic cell therapy. For example, the central nervous system with the blood brain barrier prevents the use of somatic cell therapy to repair genetic defects of the neurons.

For germ-line therapy to be properly implemented the following requirements should be met:

1. Germ-line gene experimentation should only be undertaken to correct serious genetic disorders (for example, Tay Sachs disease)
2. There should be considerable prior experience with human somatic cell gene therapy, which has clearly established its safety and efficacy.
3. There should be reasonable scientific evidence using appropriate animal models that germ-line gene therapy will cure or prevent the disease in question and not cause any harm.
4. Interventions should be undertaken only with the informed, voluntary, competent, and understanding consent of all individuals involved.
5. In addition to approval by expert panels such as the NIH's Working Group on Gene Therapy and local Institutional Review Boards, all proposals should have prior public discussion.[37]

Ultimately, the use of germ-line therapy should be undertaken as long as the goals of such treatment are the prevention and treatment of disease. This is especially true of those instances where somatic therapy is futile. In such cases, germ-line therapy, being the only means of treatment, may be obligatory.

The goal of gene therapy, both somatic and germ-line, should be the individual and not the population. "Bioethicists. . .commonly suggest that genetic therapy should be used to treat or prevent illness but not to improve our genetic heritage."[38] Gene therapy should be used for negative eugenics, the correction of disease, and not positive eugenics, the enhancement of the genome. The overall effect of such treatment on the human species should be kept in mind as the human population will be affected by individual choices in gene therapy, especially those concerning the germ-line.

> Genetic manipulation of human reproduction has the potential to multiply medical errors exponentially--sending ripples that radiate far beyond the

> finite lifetimes of gene therapist or consenting patient. Our ethical judgements, individually and collectively, ought always to reflect this profound biological difference between somatic cells -- with their short-lived genes that lie in the moral domain of individual choice -- and germ cells -- with their potentially immortal genes to which future generations also lay moral claim.[39]

In determining the value of treatment, somatic cell therapy should be left up to the individual whereas germ-line cell therapy should be guarded more cautiously. Gene banks might be a good idea to protect against the shrinking of the human gene pool.

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Chapter Six: Contemporary Determinism and Reductionism

"An age of science is necessarily an age of materialism; ours is a scientific age, and it may be said with truth that we are all materialists now."
-Hugh Elliot-[1]

"Virtually all past civilizations believed that the human form was sacred, made by God or the gods. . . .The Christian tradition gave the human body added significance through its belief that God became incarnate and suffered the joys and pains of being human."[2] In the Bible, God makes man in his image. It is this sacred image of man as a manifestation of God in the flesh that helped our American forefathers form the basis for their self-evident truths found in our Declaration of Independence. The Human Genome Project could possibly reduce this sacred image to the mechanics of six billion organic units. The Human Genome Project more than any other scientific innovation challenges many religious beliefs at their roots. And because many of our laws and social practices are rooted in our religious beliefs, the Human Genome Project stands to shatter more than just religious beliefs. The Human Genome Project could remove the foundation on which our civilization is based. Thus, it is important to look at the history and development of the reductionism and determinism in the man-the-machine metaphor that lies behind the Human Genome Project.

The concept of man as a machine is not new. Galileo, more than anyone else, led the way to the mechanistic view when he challenged the church's belief about the earth being the center of the universe. "Galileo's thinking is viewed as seminal to the seventeenth-century reduction of life to machine."[3] Galileo held that

the natural world could be explained through quantitative measurements and mathematics. To Galileo, metaphysics and spiritual studies were foolhardy means of exploring the world. As historian Lewis Mumford notes regarding the impact of Galileo:

> Galileo. . .surrendered man's historic birthright: man's memorable experience, in short, his accumulated culture. In dismissing [human] subjectivity Galileo had excommunicated history's central subject, multidimensional man. . . .Under the new scientific dispensation . . . all living forms must be brought into harmony with the mechanical world picture by being melted down, so to say, molded anew to conform to a more mechanical model. For the machine alone was the true incarnation of this new ideology. . . . To be redeemed from the organic, the autonomous, and the subjective, man must be turned into a machine. . . .[4]

Bacon, Kepler, Newton, Descartes and Boyle were other early proponents of the mechanistic view. All contributed and supported the analogy of nature as a machine, specifically the machine they knew best, the clock. Robert Boyle described the universe as "a rare clock . . . where all things are so skillfully contrived, the engine being once set a-moving all things proceed according to the Artificer's first design, and the motions . . . perform their functions upon particular occasions, by virtue of the general and primitive contrivance of the whole engine."[5] The theories of Belgian anatomist Andreas Vesalius on human physiology and the discovery of the "pump-like" circulation of blood by English physician William Harvey provided further support to the concept of living organisms as machines.[6]

Not all supporters of the mechanistic view wanted these ideas extended to human beings. Rather than advocate pure materialism, some, like Descartes, advocated a dualistic view where man possesses an immaterial soul as well as a

material body. He still believed that animals and other nonhuman organisms were "soulless automata". The movement and biological processes of these automata could all be reduced to mechanical mechanisms:

> I wish you to consider . . . that all the functions which I have attributed to this Machine, such as digesting of meats, the beating of the heart and arteries, nourishment and growth, respiration, waking and sleeping; the reception of light, sounds, odors, tastes, warmth, and other similar qualities, into the exterior organs of sensation; the impression of the corresponding ideas upon a common sensorium and on the imagination . . . and finally the external motions of all the members of the body . . . I wish, I say, that you would consider all these functions as. . . neither more nor less than the movements of a clock or other automaton . . . so that it is not necessary, on their account, to conceive within it any vegetative or sensitive Soul. . . .[7]

Furthermore, it was believed that nonhuman organisms cannot feel pain or discomfort, and lacked intelligence. Humans, to Descartes, were special organisms that composed the special entity of the soul. Possession of a soul gave humans the ability to feel emotions and pain. The church and the Neoplatonists opposed this view of nature whereas the rationalists supported and embraced this view point.

Some true materialists wanted to fulfill the church's worst nightmares and extend the mechanical view advocated by dualists like Descartes to the human mind and not just the human body. For example, the philosopher Julien Offray de La Mettrie saw humans as soulless machines with no need for God.[8] It is in the materialists that the body goes from being a sacred creation to a secular machine. The human being is transformed from being a divine image to being an engine or machine of the industrial age with efficiency as the goal. As historian David F. Channell explains:

> By the end of the eighteenth century, mechanical philosophy seemed able to explain organic life from the function of bodily organs to the creative aspects of the mind. . . . In the reductionist world of the mechanical philosophy, machines and organisms could both be explained in terms of mechanical principles. The apparent conflict between the two is resolved by reducing life to technology. Life in general, even human beings, were at their base functioning as mechanical organisms.[9]

These ideas of materialism have not disappeared, and science has continued to contradict the teachings of the church. Physical and biological laws and theories, like the laws of thermodynamics and the idea of evolution, have replaced the older ideas of spontaneous generation and divine creation. Science has continued to reduce the natural world to a mechanistic view where everything can be explained in terms of physical laws and mathematical equations. "The molecular biologist describes life and evolution in terms of information, messages, and code. . . .'the organism becomes the realization of a program prescribed by its heredity. . . . Reproduction [of its constituent molecules] represents both the beginning and the end, the cause and the aim.'"[10] "Our modern adventure began with the seventeenth-century, but that earlier age has not vanished like a marker on a line that we have passed; it is still present, with all its paradoxes and tensions, in the uncertainties and malaise of our modern consciousness," explains historian and philosopher William Barrett.[11]

These materialistic ideas are not without consequences. Historian Donald Worster points out that "by reducing . . . animals to insensate matter, conglomerates of atomic particles devoid of internal purpose or intelligence, the naturalist was removing the remaining barriers to unrestricted economic exploitation."[12] The same

would be true when the same conceptions are applied to humans. "The apotheosis of the beast-machine dogma is the new policy of patenting animals, which legally redefines the animal kingdom as `manufactures'--as machines."[13] We have already seen patents given to researchers and companies for human growth hormone and specially designed laboratory animals. It may not be long before patents are given for other human hormones, organs, or even genomes. In the end, "Culture is reduced to biology; biology, to the laws of physics and chemistry at the molecular level; mind, to matter; behavior to genes; organism, to program; the origin of species, to macromolecule; life, to reproduction."[14] As Buckminster Fuller puts it:

> Man is a self-balancing, 28-jointed adapter-base biped, an electro-chemical reduction plant, integral with the segregated stowages of special energy extracts in storage batteries, for subsequent actuation of thousands of hydraulic and pneumatic pumps, with motors attached; 62,000 miles of capillaries, millions of warning signal, railroad, and conveyor systems; crushers and cranes . . . and a universally distributed telephone system needing no service for 70 years if well managed; the whole extraordinarily complex mechanism guided with exquisite precision from a turret in which are located telescopic and microscopic self registering and recording range finders, a spectroscope, [etc.][15]

The Human Genome Project stands as the ultimate tool by which to reduce man to a mechanical model. The goal of the Human Genome Project is to reduce people to a three billion unit code that can be used to explain all aspects of human life. "Genetic knowledge is the ultimate in determinism and hereditarianism. . . . Once the structure and function of the genome is understood, once the concepts of genetic code, program, and messages are grasped, it may seem possible to have a gene-based explanation of all phenotypic characteristics, including all aspects of

human health, disease, and even behavior."[16] The goal and problems of the geneticist are analogous to those of the anatomist. The geneticist who unwraps the human genome will be unable to keep the integrity of the human being intact just as Vesalius compromised human integrity in the quest for an anatomical understanding of the human body. Both the geneticist and the anatomist, in attempting to better understand the mechanics of the human body, ultimately end up devaluing the human body. In the process of comprehension, we reduce the body to its parts. We must remember to return the parts to the whole. By returning to a more holistic view, we may restore some of the integrity that is lost.

The importance often attached to genetic information further complicates the problem. Generally speaking, "the perception has been that what is genetic is unchangeable, and that problems of criminality, behavioral deviation, individual capability, even differences between sex, race and general intelligence (IQ) can be accounted solely from within the domain of human genetics."[17] Unfortunately, life is not that simple. Many different influences and experiences stand behind whom we are. These perceptions must be dismissed to prevent the misuse and abuse of the information resulting from the project. "A misuse of genetic information could justify the destruction of all embryos less than 'perfect', the de facto creation of a new 'biological underclass', and the systematic ostracism of the 'genetically unfit.' Society could have a powerful genetic tool for controlling individuals through an entire series of labeling and intervention: a '*biopolitics of the population*'."[18] Cultural and moral interests will be at risk if these perceptions continue to be inflated. The

legal system will also be destroyed by claims blaming genes as the source of a person's actions. Application of genetic information could result in social tyranny at an unprecedented level. The presentation of the project by such leaders as James Watson further adds to the problems of perception.

> The leaders of the Human Genome Project have thus created, through their world views, a "paradigm shift" in genetics and an aggressive, simplifying, reductionistic perception of genetic knowledge and of humans. Their immediate success in research strategy has enabled them to pass persuasively from science to social implications and to express powerfully their views in the form of reductionist and deterministic generalization in advance of experimental evidence.[19]

Because many of the project leaders have an economic or personal interest in the continuation of the project, it remains important for persons from outside the project to be heard on issues surrounding the Human Genome Project. Such people may be more objective than those caught up in the Human Genome Project.

Social and environmental influences are often ignored in current debate. For example, fetal alcohol syndrome (FAS) is not caused by any genetic markers, but rather the exposure of the fetus to alcohol during pregnancy. Studies using twins separated at birth show dramatic differences even though they have the same genetic information. Evidence from such studies suggest that "a genome may reorganized itself when faced with a difficulty for which it is unprepared. . . . The types of response are not predictable."[20] Unless the importance of environmental and social influences is added to the picture, a whole new world of genetic eugenics could be practiced similar to that in Brave New World. The Human Genome Project could be the scientific innovation that brings materialism and determinism to a

climax if these perceptions are not changed. We could someday view ourselves and others as robots preprogrammed with a definite unchangeable destiny. Such an outlook removes any responsibility that individuals currently have for their actions.

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Chapter Seven: The Road Ahead

"The new technologies for human engineering may well be 'the transition to a wholly new path of evolution.' They may therefore mark the end of human life as we and all other humans know it."
-Dr. Leon Kass-

The Human Genome Project remains a project of international importance. The information gained as well as the application of this information concern each and every one of us. Genetic screening of embryos began in the 1960's, but with the knowledge from the Human Genome Project the number of available tests will increase. The screening of humans for various diseases or predispositions promises to allow people to better plan their lives. Genetic screening may also allow for more informed preventive medicine. Eventually, the results of the Human Genome Project may be used in curative medicine like gene therapy. The Human Genome Project promises to aid the health of those who can afford the new medical interventions that will be spawned from the project.

As with most new technology, the Human Genome Project raises many questions. How exactly will information from the Human Genome Project be used? Who will regulate the use of the information? What exactly will constitute defective genetic material? In contemporary society, a society so concerned with success and appearance, could not the new technology easily move from medicinal to cosmetic application? Might the pressures of a less than liberal society lead to a new kind of eugenics with unthinkable consequences? What about the confidentiality of the patient and concerns about discrimination? Finally, might it not

be possible that genes could be lost forever decreasing genetic diversity and with this loss our ability to adapt to future conditions? The question must be asked, What right do we have to irrevocably decide the future for subsequent generations? Of course, there will always be questions about economics: who benefits from patenting of genes, gene products, and genetic tests?

The future is never certain but we can make some predictions of what lies ahead. Given the current rate at which the Human Genome Project is moving, it will be completed ahead of the scheduled 2005 date. Meanwhile, information derived from the project will be applied to medicine with increasing frequency. This past fall, Genzyme, a biotechnology company in Cambridge, Mass., announced new diagnostic technology that can simultaneously analyze DNA from 500 patients for the presence of 106 unique mutations on seven genes.[1] Such technology makes it easy to test many people for multiple disorders, allowing for the set up of widespread genetic testing. Discussion has already begun in the form of international conferences and on the Internet. To help prevent misunderstanding and to allow informed discussion, the public should be educated through school programs, workshops, television, and the Internet. The time to act is now for the technology will not wait for us to catch up. The technology and information will only continue to develop at alarming rates.

The Human Genome Project offers great possibilities in terms of predictive and curative medicine. At the same time, the project poses great challenges in confronting traditional views. Robert Haynes, president of the sixteenth

International Congress of Genetics, elaborates:

> For three thousand years at least, a majority of people have considered that human beings were special, were magic. It's the Judeo-Christian view of man. What the ability to manipulate genes should indicate to people is the very deep extent to which *we are biological machines*. The traditional view is built on the foundation that life is sacred. . . . Well, not anymore. It's no longer possible to live by the idea that there is something special, unique, even sacred about living organisms.[2]

Challenges to the traditional view of humans as sacred images of God are not new, but the Human Genome Project will provide for the greatest challenge yet. Society must be ready to incorporate the new information provided by the Human Genome Project into a new view of what it means to be human. If we do not undertake serious discussion regarding the meaning of "humanity", "personhood", and "individual", we will be caught in tremendous turmoil between clashing viewpoints with no middle ground.

In the building of a new conception of humanity, it will be important to look for guidance in the traditional views found in religion. "Religious traditions offer insights about the value and significance of the human body . . . the human body is created in the image of God and therefore there are limits on what human beings can do with their own bodies and those of others," notes Kimbrell.[3] Although the new idea of the human body might be different from that found in traditional religious views, it need not be radically different. Just as many people have come to reconcile the differing ideas of creation and evolution, we may some day be able to do the same with the new and old images of what it is to be a human being.

The information derived from the Human Genome Project must be managed

and applied with caution to prevent terrible atrocities from occurring. Jersild and Johnson insist, "Whether one is a determinist or a believer in self-transcendence, the Human Genome Initiative [Project] may provide information that makes it possible to influence human destiny through biological engineering. Instead of being driven by our genes, we may be able to reorder our genetic code to change the very nature of human nature."[4] We must be careful in implementing genetic screening and gene therapy programs. As a lead editorial in the New York Times notes, "Humans . . . [are] biological machines . . . that now can be altered, cloned and patented. The consequences will be profound but taken a step at a time, they can be managed."[5] Because we are human and make mistakes, we should be careful using the new resources of the Human Genome Project.

> We are by no means God's equals, even if we are in some sense co-creators. . . . technological advances cannot vanquish original sin. . . . HGI [HGP] may provide us with the power of knowledge and the opportunity for attaining a new and unprecedented level of human health, but it may also provide us with opportunities to exercise our greed and shortsightedness so as to open up new depths of human injustice and misery.[6]

We will need to look to the future and future consequences of our actions more than ever with the application of information from the Human Genome Project. Once a gene has been eliminated from the genome it is gone forever. According to Kimbrell, "Rather than eliminate human genes viewed as inefficient, we should celebrate our diversity. We should apply the same principle to other members of the living kingdom, using genetics to better understand and protect our dwindling species rather than to genetically engineer the natural world toward efficiency."[7]

The paths we take may be largely guided by societal expectations rather than governmental regulations. As Tocqueville feared, the tyranny of the majority can be more unjust and cruel than the tyranny of the state. Before we act in ignorance or arrogance, we should attempt to fully understand the possible consequences of our actions. The future is unknown, but we can do our best to act in an informed and intelligent manner.

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