CHAPTER 10

Health Care Ethics and the Near Future

GOAL

To understand the various areas of biological research and the moral problems associated with them.

OBJECTIVES

Upon completion of this chapter, the reader should be able to:

1. Understand the purpose, practice, benefits, and dangers of genetic screening.
2. Understand the benefits of prenatal genetic testing and how it leads to the moral issues that surround abortion.
3. Describe the dangers of utilizing genetic research for the purpose of eugenics.
4. Explain the promise of the human genome project.
5. Understand the scientific advances possible with recombinant DNA as well as the dangers that unregulated research can create.
6. Put all the issues that are raised in this chapter in the context of the Faust legend.
7. Explain how ethical problems with genetics make necessary a new virtue of family planning with guidelines that help us utilize genetic counseling in an ethical manner.
8. Explain the promise and ethical pitfalls associated with gene therapy.
9. Create a policy statement that provides an ethically suitable direction in regard to cloning technology.
10. Explain the posthumanist position regarding genetic science and the discussion of ethics.
11. Explain the current state of stem cell research and provide a pro and con argument for its continuance.

KEY TERMS

allele
dominant gene
eugenics
gene therapy
genetic carriers
genetic disease
genetic predisposition
genetic screening
genome
heterozygous
posthumanism
recessive gene
recombinant DNA
regenerative medicine
stem cells

> *Rebuild your world, rebuild your race, and rebuild your empire. Rebuild it all. But make sure you rebuild your ideals too. Rebuild the principles that made you a great and honorable galactic power in the first place. Don't prey on the weak. Don't steal from the helpless. Don't murder the innocent. Be a force for good, not a force for yourself.*
>
> Dan Abnett, *Doctor Who: The Silent Stars Go By*

GENOMICS AND MEDICAL PROGRESS

It is the vastness of the genetics enterprise that is so overwhelming. We may be approaching that moment in history when we can choose not only how we are going to live but who we are going to be. We are perhaps at a watershed moment, bigger in impact than the grand ideas of capitalism, socialism, or Darwinian evolution combined. The impact may be larger than the technological advances of dynamite and computers, and more significant (assuming that it did not kill us) than a meteor strike. In the end, how we answer the basic questions thrust on us by this revolution in biology will shape our philosophy, our science, our technology, and the very way we think about humans and humanity.

The human **genome** project, which provides a complete list of the chemical letters that compose the map of the human genome, has been completed. The promise of this information and its potential application is remarkable and may change the nature of health care itself. The psychologist Thomas Bouchard has said, "For almost every behavioral trait so far investigated, from reaction time to religiosity, an important fraction of the variation among people turns out to be associated with genetic variation."[1] Does this mean that all of the small idiosyncrasies that make us unique humans (both lovable and frustrating) are within our grasp to change? What we have not seen yet is the project's full application, but we are beginning to see a number of specific medical treatments based on the information. What is perhaps missing is the overarching vision that provides the way forward beyond the initial steps.

HUNTINGTON'S DISEASE

One day a woman's father comes home and starts ranting and raving. She has never seen him like this. His limbs begin moving in strange ways, and he begins to have seizures. Finally, the doctors have the diagnosis: Huntington's disease. Now she finds out that, because her father's disease is the result of a **dominant gene**, she has a fifty-fifty chance of getting it herself.

Huntington's disease (HD) affects men and women equally across all ethnic and racial lines. Approximately 30,000 people in the United States have the condition. This is a devastating disease, without a cure, that affects the patient's ability to think, talk, and move. Over time, these symptoms may progress to a stage where the person loses the ability to recognize familiar objects, people, and places.

There is no cure; the treatment emphasis today is on palliative measures (living positively with Huntington's disease), consisting of an integrated, multidisciplinary approach that focuses on the triad of:

- diet and supplements
- exercise
- spiritual and psychosocial support

Huntington's disease most commonly develops between a person's thirties and fifties. One often finds out only after having passed the disease to one's own children. If the damage has already been done, is it better not to know? After all, 50 years is a lifetime, even if it does not match our average life expectancy. Still, there is great hope that researchers will find a cure.

IN THE NEWS

CRISPR

What if you could cut out a target gene within any cell, and if needed, replace it with another gene, and then neatly stitch the ends of the DNA back together? This is the promise of CRISPR, a new technique potentially offering a cure for diseases such as Huntington's, muscular dystrophy, and sickle cell. The gene-editing technique developed in 2012 at the University of California, Berkeley enables scientists to snip out a piece of any organism's DNA, much like a film editor splices a film reel.

CRISPR differs from traditional forms of gene therapy as it can be used to edit genes on the human germ line, so that the changes made are passed down through the generations, permanently changing the gene pool. This would erase the disease from the person's germ line, so future offspring would also be spared. On the darker side, this capability gives rise to concerns about the creation of mutants and designer babies. However, the technique suffers from a serious problem: currently we do not know what we do not know.

A recent trial of the technique in China where scientists attempted to modify the germ line of 86 human embryos by removing a defective gene that causes a deadly blood disorder resulted in only four embryos that manifested the new gene replacement; however, the modification also created a series of other inexplicable mutations in genes that weren't targeted by the researchers.

In response, an international group of scientists called for an immediate moratorium on inheritable human genome editing until risks can be assessed. Unfortunately, the group has no regulatory power over the practice and cannot stop a rogue scientist somewhere from creating a "Frankenbaby."[2] We are in a new age, where, as Yogi Berra warned us, "The future ain't what it use to be," and "You've got to be very careful if you don't know where you are going, because you might not get there."

1. Given the potential for good, should we continue this research using human embryos for research that alters the human germ line?
2. Can you ethically do research on human embryos when some of the outcomes are mutants?
3. Some scientists have suggested using the technique to produce Aedes mosquitoes (the type that carry the Zika Virus) that can only produce sterile offspring. If the altered creatures were released into the environment they would rapidly control the numbers of Aedes mosquitoes, perhaps even cause their extinction. Is the fear of not knowing what you don't know enough to stop the use of this technique in non human species even to solve an important medical problem? Do we care about the extinction of the Aedes mosquitoes?
4. A group of scientists using this technique are in the process of creating a very wooly hybrid mastodon/modern elephant that could survive in colder climates. Should this be done? Would you support this use, even if it solves no problem, but would be interesting?

However, the great hope that we have is associated with potential danger, for knowledge is power, and the knowledge gained in finding the Huntington's gene is the same as that used in bioengineering—potentially one of the greatest but also most dangerous developments of human intelligence. But the stakes are high—about 20 percent of birth defects are caused by genetic or hereditary factors. Should we just let **genetic disease** continue if we have the power to stop it or at least lessen its impact? The consensus so far seems to be that we should move forward, but we should be clear regarding what it means to move forward in this area.

CASE STUDY

The Future Is Almost Now

In the not-too-distant future, given our developing knowledge and statistical abilities, medical science may allow health care providers to take a DNA sample from a fetus and create a vast probability chart—a type of medical horoscope for the infant. From this, one could fashion a lifestyle precisely tuned to our genetic predispositions:

- We may find that we can smoke without fear of cancer.
- We may need to avoid red meat to avoid a stroke in our mid-forties.
- We may be able to not worry about using sunscreen on the beach.
- We may find that we should avoid living near or working at manufacturing plants that create plastics.

Our knowledge of genetics may free us from a whole range of fears that health care professionals feel obliged to warn the whole population against. Instead of following every "good for you" health rule, we can be more precise and personal in our health care efforts. On the other hand, the probability chart may warn us of a future horrific illness.

1. How do you think that a yet-to-come diagnosis would affect you today?
2. Are you ill if you have the diagnosis of a horrific condition in the future?
3. Should your health care insurance costs be targeted to account for the horrific condition?
4. Should future employers be provided with your probability chart?
5. What if the predisposition is for a horrific disease without a current cure? Could the personal probability chart become the basis for the ultimate preventive medicine, abortion?

While the human genome project was pure research, we have now moved forward into application. Is now the time to ask ourselves what we are to do with this knowledge? Those fearing the potential of genomics could point to the character of Faust (or Dr. Faustus) to show how one can be led astray by the unquenchable thirst for knowledge. Dr. Faustus is a scholar so determined to possess more and more knowledge—especially concerning the deepest subjects such as the secret of life and afterlife—that he is willing to trade his soul to the devil for it. Faust makes the bargain and is happy with the bargain until the devil comes for his payment. In the same way, we will be happy with what our knowledge will bring us, but we will be devastated when we are called upon to pay the fee. Like Icarus, we will fly too high, and our wings will melt. This is, in fact, how Marlowe understood the character of Dr. Faustus.

> Till swoll'n with cunning, of a self-conceit,
> His waxen wings did mount above his reach
> And melting, heavens conspired his overthrow![3]

The point of the Faust and Icarus stories is generally that humankind should recognize its limitations; the failure to do so is to commit the sin of excessive pride or hubris. In secular terms, we say that humankind is in danger of overreaching its proper boundaries.

The key worry behind overreaching is that there is inevitably some disaster that comes as a result. The question is whether there will be any such fee, for no one has made any pacts with the devil in setting up the human genome project.

Some argue that there are no limits to human knowledge and that there shouldn't be. Such fears, it could be argued, are the result of theological beliefs that are no longer held. The theological basis for the Faustian view is that humans have a predetermined place in the scheme of things, and to move beyond this predetermined place is sacrilegious. Religious people do tend to believe that humankind has a place in God's plan, but most are not terribly sure that the quest for knowledge interferes with that plan; indeed, one can easily imagine that our place is to seek knowledge as a way of better knowing God's plan. For those who are not religious at all, there is no problem with God's plans in the first place. Environmentalists sometimes think of humankind as occupying a certain place in the natural order, but doing so is quite consistent with an unending quest for knowledge. There are dangers, to be sure, but they arise only when knowledge is applied.

There is a worry on the other side of the question—worry that we will put up artificial barriers to our knowledge and stop short of great discoveries that will radically increase the quality of life. Imagine if we had refrained from discovering the causes of various diseases that we have learned to cure or prevent. The fear is that we would be doing something similar if we stopped now in our quest for knowledge. Fears of the improper extension of human knowledge therefore seem to be unfounded unless one believes that the application of knowledge inevitably follows its acquisition. The question ultimately comes down to whether mankind can be trusted to use (or not use) the knowledge in question.

Modern science has achieved more than we could have dreamed possible. There is no denying the good that science has done for us. On the other hand, there is no doubt that the dangers are just as great as the benefits we have gained. Can we go too far in our attempts to understand nature? Have we gone beyond the limits of human responsibility? These are questions that arise when we consider current research and applications in genetics, and attempt to use this knowledge for the improvement of human life. Genes are the basic carriers of the information that makes us what we are. If we reach the point at which we understand these biological building blocks, will the power that comes with such knowledge be too much for humanity to use responsibly? These same questions were raised with the development of atomic science and have yet to be adequately resolved. For example, antinuclear activists argue that the consequences of a nuclear accident at a power plant outweigh the possible benefits of the plants in operation, and that the problems with waste disposal have yet to be overcome. Such questions are arising more and more in all areas of science, but genetic science has possibly the greatest potential for good and ill.

Historically, regardless of whether you were thinking about disease prevention, or therapy, the medical model was one that viewed the patient as an individual, a representative of humanity, or perhaps a representative of a large important subset, but always an individual. Genetic information is exceptional when compared to other medical information about a patient as genetic conditions are family problems. A diagnosis or a finding of a genetic predisposition in the individual has implications for other family members, which opens the ethical duty of preventing harm or risk jeopardizing the health of others. The applications of this information are enormous, as they potentially allow the physician to diagnose a future ailment, as well as individualize therapy at a level never before possible.

The biblical phrase, "through a glass, darkly," is an apt description of where we currently stand in regard to genomic medicine. One can't help feeling that we are entering a time when medicine itself will be irrevocably changed and that we are only in the beginning stages. It is unclear where the path will take us, what knowledge will be acquired, what skills will need to be mastered, what to avoid, and what attitudes we must form as genomic medicine expands into a variety of areas.

Because of the scientific complexity of these advances, especially in the areas of genetic science, there is a great need for educating and training all medical students, physicians, and clergy in genetic counseling. Genetic counselors and other specialists with experience in genetics and counseling will play an integral part of the health care team providing information and support to individuals and families.

In this chapter, we will examine recent developments in genetic science, particularly as it applies to medicine, and attempt to determine how we should negotiate our way through the forest of ethical issues that arise when we seek to understand and employ our understanding.

GENETICS AS SOCIAL POLICY

What ethical issues arise when we consider the possibility of turning genetic testing into social policy? Some suggest that all parents be tested for genetic diseases in order to avoid the social and personal costs of genetic impairment. Others worry that this will lead to a coercive policy of abortion or of preventing parents from having children. Such policies raise still further issues when they are directed to certain ends, as they are with eugenics. **Eugenics** is the practice of manipulating the genes of offspring through either breeding or genetic alteration. Should we attempt to eliminate some or all genetic abnormalities? Should we attempt to improve the race of human beings by increasing intelligence through genetic selection?

> *The children of the good parents they will take to a rearing pen in the care of nurses living apart in a certain section of the city; the children of inferior parents, or any child of the others born defective, they will hide, as is fitting, in a secret and unknown place.*
>
> Plato, *The Republic*, Book V, 460C (380 B.C.)[4]

It is clear that Plato is referring to the practice of infanticide for diseased or disabled newborns. It is also clear that this practice is conceived to be part of a more general practice of eugenics, for Plato goes on to say, "if the breed of guardians is to remain pure." Sometimes what we think to be new choices are really quite old. After all, stock breeding is a form of eugenics. The dairy cow of today is a far cry from the wild cow from which it is descended. Our most recent experience with eugenics came when the Nazi experiments on human beings were revealed. It is therefore understandable if people are a bit apprehensive over any renaissance of eugenic ideas. Nevertheless, we should always give proposals a hearing lest some suspect that we are avoiding discussion out of fear of the truth.

The ability to screen and prenatally test for genetic disease raises the possibility that we could eliminate genetic diseases with a policy of negative eugenics or even improve the genetic pool of humanity by selecting for positive attributes—positive eugenics. A moderate policy of eugenics that has the intention of eliminating the most serious genetic diseases seems sensible enough, but even such a moderate approach is fraught with difficulties. The number of people carrying a recessive gene is rather large, and it is difficult to justify preventing such people from reproducing merely because they have a recessive gene. Given that it is impossible to have a genetically impaired infant with only one parent contributing a recessive gene for, say, sickle cell anemia, it would be hard to justify preventing such a couple from having children. On the other hand, if we do not eliminate these recessive genes, we will never overcome genetic disease.

An extreme program of negative eugenics faces practical difficulties that make it almost, if not in fact, impossible to implement. Could we eliminate all genetic disease? Since the majority of people carry at least one recessive gene for some genetic disease, a radical policy of negative eugenics would eliminate a large portion of the human population. But there is a more important question to ask: Would we want to eliminate all genetic disease? There are dangers involved in shrinking the gene pool. Our resistance to various sorts of biological attack is dependent to a great degree on our genetic variety. Take, for example, sickle cell anemia. We know the disease only from its negative effects here in the United States, but in malarial Africa, where the disease developed, being a carrier of the disease functions to ward off the effects of malaria.

A program of positive eugenics—here understood to include not only breeding but genetic intervention—attempts to improve the gene pool by increasing the numbers of those with positive attributes. Polls have shown that if this technology were available, many parents would make use of it. It is unlikely that we could ever develop anything like a "superhuman," but parents may be able to specify specific traits they would prefer to hand down to their children. There would be pressure upon parents (and the same would be true of nations) to utilize positive eugenics in order to increase their children's chances in a competitive market. But the problem ultimately is a scientific one; it is almost impossible to imagine a successful scientific program of eugenics, positive or negative. At this stage, the conclusion seems to be that our best course of action is to use genetic testing to help individuals rather than to alter the genetic makeup of humanity.

The names *Eugene* and *Eugenia* mean "well born" and share their entomological foundation in the ideas of eugenics. While we admire the beautiful people among us, it is often the nerds who become the more interesting people. Would a world of Eugenes and Eugenias be as interesting?

GENETIC ENGINEERING

> The recombinant DNA process is the most dramatic technological tool to date in the growing biotechnological arsenal. The biologist is learning how to manipulate, recombine and reorganize living tissue into new forms and shapes, just as his craftsmen ancestors did by firing inanimate matter. The speed of the discoveries is truly phenomenal. It is estimated that biological knowledge is currently doubling every five years, and in the field of genetics. . . We are virtually hurling ourselves into the age of biotechnology.[5]

Research into **recombinant DNA** is indeed a marvel of modern science, but it also brings forth some of the greatest fears of all. Scientists are now genetically altering organisms for various purposes. We have heard about genetically altered fruits and vegetables, but the range of experiments is extremely varied. The fear is that experimenters will develop organisms that will endanger humans or other living beings. The possibilities are the stuff of science fiction, and such fears have led to calls for restricting this research or even banning it altogether. Such calls have increased in recent years, and many argue for a complete ban on genetically altered foods. Additional issues have arisen concerning conflict of interest among scientists who are supported by government but turn to the marketplace for additional compensation. Some worry whether scientists can be trusted with the awesome responsibilities that come with such dangerous research. Can we rely on scientists to take the necessary precautions to keep the organisms they create harmless to human beings?

IN THE NEWS

The Synthetic Future

Genetically modified organisms (GMO) are not new. According to the USDA, in 2009, 93 percent of soy, 93 percent of cotton, and 86 percent of corn grown in the United States was GMO. However, in 2010, life on earth as we currently understand it, changed. By inserting computer-designed genetic material into a bacterial cell, scientists created an entirely new strain of bacteria, a new life form, the world's first synthetic cell. In announcing his creation, scientist Craig Venter called it the first life on earth "whose parent was a computer."[6]

1. Do you favor the creation of GMO crops? Defend your answer.
2. Do all GMO products need to be labeled as such?
3. Are we really ready for a life form whose parent is a computer?
4. What precautions would you like to see put in place—perhaps a suicide gene implanted in these new life forms to assure us that they cannot survive outside the lab?

GENETIC TESTING

Advances in genetic testing have the potential to revolutionize how physicians diagnose and treat patients. Currently there are more than 2,000 genetic tests available to physicians to aid in diagnosis and therapy for more than a 1,000 different diseases. Gene testing is generally performed for the following reasons:

- conformational diagnosis for a symptomatic individual
- presymptomatic testing for estimating risk of developing disease
- preymptomatic testing for predicting disease
- prenatal diagnosis screening
- newborn screening
- preimplantation genetic diagnosis
- carrier screening
- forensic screening
- paternal testing[7]

For example, we can test couples for sickle cell, a disease that deforms red blood cells into thin, elongated sickle-shaped forms and causes anemia, cough, and muscle cramps. Sickle cell occurs only when both parents are **genetic carriers** of the **recessive gene**. If both parents are carriers, there is a 25 percent chance that the child will have the disease. Is this too much of a risk for parents to take? Depending upon how paternalistic we are, we might (1) not allow them to have children, (2) suggest strongly that they do not have children, (3) refuse to pay the medical expenses (this would be a decision for insurance companies and/or government), or (4) merely leave it up to the parents whether to take the risk. Most would leave the decision up to the parents, but some would argue that the parents should not be allowed to have a child when the risk is so high. It is argued that it is unfair to bring a child into the world knowing that it will have such a heavy burden to bear.

Sickle cell is instructive, however, in that it is a disease that primarily afflicts people of African descent. To refuse to allow people children who are members of a minority may suggest racist motives. But there are other diseases that are not so selective. Are we to restrict people afflicted with nonracially connected genetic disease? Many people believe that it is their right to bear children, however they turn out. It is further argued that there are many afflictions that are not genetically caused or cannot be tested for. Why might such people be allowed to be born but not those with a disposition to diseases we can test for? The assumption here is that existence is a good thing; for some it may not be, and then testing would be preventing injury. This raises a deep problem: Can existence be an injury?

At first glance, human existence could be understood as an injury in utilitarian terms if the prospective life would likely contain more unhappiness than happiness. But this will not do, because ordinary life is a veil of tears for many people. To be useful for our purposes in the argument that asserts that existence can be an injury, it must be the case that bodily or mental impairment must be significantly greater than that which most people must face. This is certainly true for many diseases, and this would provide us with grounds to argue that existence can be an injury; therefore, it would be immoral for such a person to be brought into the world.

Some argue that the perspective employed in such an argument is not the correct one. The proper perspective is that of the person afflicted, and from such a perspective any sort of existence may be preferable to none at all. It may be that great suffering may be endurable if just a little happiness is possible, and this is almost always the case. There is also the problem of anticipating what a future person would prefer. Given the difficulties of such calculations, some argue that there can be no good argument against having children.

A middle ground may be found by referring to actual cases. Some diseases offer only a brief and painful existence, while others are so seriously painful and prolonged that the question of a worthwhile life is out of the question. On the other hand, some diseases are not as severe. Take, for example, Down syndrome. Children with Down syndrome are afflicted with serious problems, but the severity varies widely. It is often pointed out that children with this condition frequently lead happy lives.

Some argue that we must also never underestimate the human spirit and its ability to overcome adversity. As a notable example, Helen Keller is known for having overcome devastating odds to lead a fulfilling life. The response to this argument is that one case does not a policy make. We must ground any moral policy in the reality of the overwhelming majority of cases. Policy should aim at the majority, and exceptions to the rule—the hard cases—should be regarded as exceptional. It may be too much to expect that all those with Helen Keller's afflictions be able to achieve what she did.

IN THE NEWS

Can You Handle the Truth?

A Silicon Valley firm created a personalized testing service for $99.00, enabling customers to send a spit sample and get back a detailed picture of their genetic makeup. The report provided an analysis of their ancestry and also told them whether they have genes predisposing them to any one of 254 hereditary diseases, including diabetes, heart disease, and breast cancer. In November 2013, the Food and Drug Administration (FDA) ordered the company to stop issuing the health analysis component of the report.[8] The company had to seek approval from the FDA to provide these health reports to their customers. Almost two years later, in October 2015, the company succeeded in getting approval to offer customers information on 36 inherited disorders, far fewer than the original 254 diseases.

1. Is this overreaching paternalism or rational regulation?
2. What can an individual do with information that tells them they are prone to heart disease, cancer, or Alzheimer's disease? Is it useful or dangerous?
3. Should medical analysis be provided in this manner?
4. Should individuals receive this information without appropriate genetic counseling?

Many people have **genetic predisposition** to certain diseases (such as cancer) and to react to toxic chemicals that cause diseases. Roughly 10 percent of the population has bodies that produce enzymes that combine with hydrocarbons and produce carcinogenic substances. One can imagine companies refusing to hire potential employees who are genetically disposed to diseases caused by the toxic chemicals used in certain industries. In fact, this is already happening. One can assume that as actual testing becomes common, the possibilities for discrimination will be great. Given that we have no control over our genetic makeup, the fairness of such practices must be questioned. Genetic discrimination and the fear of it would have a negative effect in the delivery of clinical care. In 2008, the Genetic Information Nondiscrimination Act (GINA)[9] passed protecting individuals from genetic discrimination by health insurers and employers. GINA prohibits the following:

- Health insurers may not use a person's genetic information in determining eligibility or premiums.
- Health insurers many not request or require that a person undergo a genetic test for underwriting decisions.

- Employers may not use a person's genetic information in making employment decisions such as hiring, firing, job assignment, or any other terms of employment.
- Employers may not request, require, or purchase genetic information about a person or their family members.

LEGAL CASE STUDY

The Case of the "Devious Defecator" (2012)

The grocery warehouse knew it had a problem when piles of human poop were found in the aisles. In that it had to be one or more of the employees, the company made a list of potential employee suspects and asked them to voluntarily submit to DNA testing.

Two of the workers, worried that they would lose their jobs if they refused, allowed a technician to brush the inside of their cheeks with cotton swabs and have the samples tested. The tests came back negative; neither man was the "devious defecator," as a judge later dubbed the culprit.

Later the workers acquired legal representation, stating they felt humiliated by the event, and also afraid that the DNA findings might be used by the company in the future. The suit was brought under the federal Genetic Information Nondiscrimination Act (GINA), which states that employers and medical insurers are not allowed to collect genetic data. The men won their suit and a federal jury granted the men $2.2 million in damages.

GINA was passed so that people wouldn't be afraid of getting DNA tests for legitimate medical or research purposes. The statute plainly says that employers cannot "request, require, or purchase genetic information with respect to an employee." This is the first GINA case to go to trial, and sets a crucial precedent for labor law. The plaintiff's lead counsel says the huge award will make other companies think twice about requiring these illegal tests.[10]

THE ROLE OF PARENTS

Virtue ethics gives us a special perspective on this question. It is the role of parents to make many decisions for their children, including the decision of life and death (or nonexistence) prior to conception and birth (assuming one is pro-abortion). One can construct a virtue ethics position that puts the decision completely in the hands of the parents. Thus, if a couple wishes to take on the burden of raising a child with a severe illness or disability, it is morally acceptable. It must also be added that having such a child would entail duties that would go beyond those that parents of normal children would be required to assume. (Society may also gain a voice in the decision if the cost of raising the child is carried by society to any great extent. Is it legitimate knowingly to bring a child into the world with serious disease or disability when one also knows that one cannot pay the expenses?) Prior commitments to society must be made if one takes on a risk knowing that society may very well have to carry part or all of the economic burden of tending to a child's health. But this perspective also puts the decision not to have children (or to abort) completely in the hands of parents. This would mean that parents would have the right to abort a child with characteristics that many would consider acceptable. Take, for example, the case of the child with Down syndrome. A couple may have a wish for a child who can share in their preference for a rather intellectual existence, an existence that is out of the question for any Down syndrome child.

Many would accept the virtue ethics perspective when it indicates that parents may bring a defective child into the world if they wish but they would not accept the alternative side of the equation that permits parents to abort children deemed unacceptable to them for less than extremely serious reasons. Clearly, one's position on the abortion issue and the concept of personhood comes into play. If one is inclined to accept abortion, then both sides of the virtue ethics perspective make sense. If one does not accept abortion as a morally acceptable practice, then one would argue that it would be acceptable to refrain from conceiving such children but that it would not be acceptable to abort such a child once conceived.

THE POLITICS OF SCREENING

Testing large populations (screening) has a checkered history. The early sickle cell anemia screening laws are instructive. The science of testing got caught up in a whirlwind of well-intentioned legislation in the early stages of the civil rights movement. It was a way of doing good for African Americans, a group of people who were becoming increasingly politically important. But legislators are not scientists. The early legislation was often poorly written and sometimes directed at the wrong target populations.

One consistent mistake was to refer to carriers of the sickle cell as diseased. To have the disease, one must have inherited the **allele** from both parents, whereas carriers have inherited the allele from only one parent. An unanticipated problem came up as paternity discrepancies arose. If a child turned out to be **heterozygous** and neither parent was heterozygous, then it became clear that someone else was involved in the reproductive process. There are many instances where this sort of revelation has led to the breakup of otherwise stable families.

Other mistakes occurred. The state of Virginia, for example, mandated that all convicts be tested for the disease, when inmates generally have few immediate plans for reproduction. Some states used testing methods that were not the most accurate available and thus achieved an unacceptably high number of incorrect positive results. Finally, there is the issue of confidentiality. Few states were prepared to protect the confidentiality of the patients. It was feared that discrimination in employment and insurance would result, or at the least that a social stigma would be attached to those identified as carriers. The lesson of the sickle cell experience shows us that **genetic screening** requires wisdom, sensitivity, and most important, good science. We must not allow well-intentioned proposals to become practice without paying close attention to the procedures and the consequences.

RECOMBINANT DNA

Research application of the knowledge gained from the human genome project is likely to be in the field of recombinant DNA. Scientists recombine the genetic material from one organism to another for various reasons. Sometimes it is done to improve a plant in some way, for example, to make it less susceptible to spoilage and damage, to ripen it sooner, and so on. Scientists also recombine DNA to create organisms that will attack pests of one sort or another. There have been attempts to create an organism that eats oil, for use in dealing with oil slicks. And, of course, the future holds the prospect of genetic intervention in human beings, either to combat disease or to eliminate a propensity for disease. The possibilities are endless.

Our experiences with nuclear physics give many cause for concern, and the fears associated with genetic research are similar. One fear is that such knowledge will be used by the military as another way to kill people, with disastrous results for both victim and victor. If a genetically engineered virus or bacteria were used, it would be difficult to contain and could attack us as well.

But even the peaceful uses of recombinant DNA technology are worrisome. One never knows if some experimental creature will interact with the natural environment in some negative way. Will we inadvertently create a modern-day Frankenstein's monster? The most commonly used bacterium is *Escherichia coli*, which is found in the stomachs of all human beings. Most creatures created by humans do not do well in the natural environment and are likely to die outside the laboratory, but since the attempts are precisely to create creatures hardy enough to fulfill our purposes in nature the prospect does hold some dangers. Scientists do employ special protocols for dealing with altered genetic materials, so it is unlikely that something will just be flushed down the drain where it can enter the natural environment, but as the technology becomes more common, it is likely to be in the hands of people who are not so careful.

The difficult training one must go through to become a genetic scientist will naturally restrict the numbers of those involved, but it is not always the case that people trained in the sciences are also conscious of their ethical duties. There is even one case of a scientist working on an organism to combat a disease affecting trees who was so upset at the delays the regulators were putting him through that he released the organism into the environment on his own. This is the kind of behavior that worries people. Nevertheless, the benefits we may reap from genetic engineering are too great to ignore.

GENETIC PHARMACY

One positive result of genetic engineering has been the development of the genetic pharmacy. Pharmacogenomics is the study of genetic variations that influence individual response to drugs. It combines traditional pharmaceutical sciences such biochemistry with an understanding of common DNA variations in the human genome. Knowing whether a patient carries any of these genetic variations can help prescribers individualize drug therapy, and decrease the chance for adverse events, and increase the effectiveness of drugs.

Anticipated benefits include: (1) more powerful drugs targeted to specific diseases, and maximizing therapeutic effects and minimizing damage to nearby cells, (2) better, safer drugs, in which recovery time will go down, and safety will go up, and (3) more accurate methods of determining appropriate drug dosages. Genetic pharmacy is one of the most productive and promising applications of genetic engineering.[11]

GENE THERAPY

"It is a profound truth. . . that nature does not know best; that genetic evolution, if we choose to look. . . . is a story of waste, makeshift, compromise, and blunder."[12]

Genetic engineering raises the possibility of direct genetic intervention into human beings. Copies of a normal gene are injected into a cell with defective or nonpresent genes. Then the DNA of the cell is induced to incorporate the new gene so that the cell may function properly. If all goes well, when the cell reproduces, it passes along the new gene rather than the original. Eventually, the patient acquires a population of good cells that will carry out the proper functions. This method is most likely to be effective when the problem is caused by a single defective gene. Huntington's and sickle cell are this type of disease (monogenic). When a disease is the result of a combination of genes (polygenic), the potential for genetic treatment is further off, and most diseases are polygenic. Although **gene therapy** is extremely difficult, researchers are pushing ahead.

Scientists at the National Institutes of Health, for example, are treating cancer patients with gene therapy. Some have argued that we are moving too fast into human experimentation.

The speed at which we proceed is always a problem at the forefront of science and medicine, but the incredible power of gene therapy cautions prudence. We must be very sure that our attempts to improve the hand that nature deals us do not end up making things worse. For example, while the modification of somatic cells (cells that do not affect the genetic makeup of one's children) raises some moral issues, the modification of germ line cells brings us back to the whole issue of eugenics, with the attendant difficulties. Even short of altering the genetic course of the human race, there are important issues to be raised.

Currently, many parents keep having children until they have one of the sex they prefer. As minor as this consideration is, genetic engineering can help by making sure the first child is a member of the sex preferred by the parents. One obvious problem of giving parents this power is that we may experience an imbalance of males and females. Even now, there are areas of the world where having a female child is regarded negatively, so if the technique of sex determination ever became widely available, problems could result. There is also the question of whether it is right to determine the sex of one's child. What if one chooses the sex, say, male, and the child later learns of the decision? Some might not care. Others might question their whole personality.

THE GENETIC CAUSES OF BEHAVIOR

A family in the Netherlands was found to have a mutation in a gene that coded for monoamine oxidase, a neurotransmitter that metabolizes adrenaline. The end effect of the mutation was that the affected individuals were constantly caught up in an adrenaline rush that signaled a flight-or-fight situation. The defect was on the X chromosome; women in the family generally were carriers of the defect, and its expression came out in the men. Research into the family history showed that half the men were angry, hostile, and antisocial and possessed low IQs.[13]

Suppose that these men were involved in a higher incidence of violence and antisocial behavior than others in the community. How much should the fact that one had a genetic predisposition toward violence, was abused as a child, sexually molested by a religious leader, or were currently attempting to give up smoking mitigate in a criminal case? Could a person truly be guilty if he had a "criminal gene"? If we decide that it is the gene, not the criminal act that we should focus on, what does this do to the criminal justice system?

Although we are not likely ever to be able to fine-tune the behavior of individuals, even crude genetic modification of behavior could pose risks. One can imagine that some political leaders might prefer passivity for most of their citizenry. Or a political leader might prefer extremely aggressive people to populate the armed forces. Behavior is likely to be polygenic and substantially environmental, so that genetic engineering of this sort is unlikely. Nevertheless, there are some scientists investigating the genetic basis of criminal behavior. Imagine a case in which the presence of a certain gene causes 30 percent of those with the gene to engage in criminal behavior. Also imagine that the other 70 percent turn out to be the leaders of societies. What would be the appropriate action, if any, to take under these circumstances?

Some have suggested that all behavior is mediated through our genes and may be within our reach to modify. Just as we might find the "criminal gene," which predisposes to a life of crime, or the "homosexual gene," which leads to alternate sexual choices, it is possible that we might find the "religiosity gene," which shapes our willingness to believe in God and to strive to live a moral life. How much are we willing to change?

CASE STUDY

A Matter of Justice

In the 1980s a woman was brought to trial for the murder of her mother. As a defense, her lawyer argued that her family suffered from the genetic defect that leads to Huntington's disease and that her aberrant behavior was perhaps the first sign of its onset. Given that her father had died of the disease, she had a 50 percent chance of inheriting the genetic condition. The judge deciding the case did not accept the argument, and she was convicted. However, some years later, the woman began to display the symptoms. The judge recalled the case and ordered her release.

1. What was the correct decision: the first, which sent her to prison, the second, when she was released, or were both decisions correct?
2. If our future is in our genes and her guilt was removed by the facts of her genetic makeup, what does this say about (a) individual responsibility and (b) the morality of a criminal justice system that is focused on individual acts?

CLONING

IN THE NEWS

Cloning Human Embryonic Stem Cells

Cloning is now possible by inserting a skin cell from a baby into an unfertilized human egg that has had its own DNA removed. This produces a blastocyte (an undifferentiated embryonic cell), which includes stem cells identical to the baby's. With this technique it is possible to make genetically identical embryonic stem cells from any cell in the human body. This would remove the need to harvest these cells from existing embryos.

Theoretically these stem cells could be grown into a variety of cell lines and organ tissues. The current research is aimed at creating genetically matched tissues, as replacement body parts; however, it is not a stretch to see that the technique could also be used to make genetically identical human beings—clones. Because of this potential some medical ethicists say the new technique points to the need for a legal ban on cloning human beings. Cardinal Sean O'Malley of the U.S. Council of Bishops called the research immoral: "Human cloning treats human beings as products, manufactured to order to suit other people's wishes."[14]

1. Do you agree with Cardinal O'Malley's argument against human cloning? Explain your answer.

Continues

Cloning Human Embryonic Stem Cells (cont.)

2. Should human cloning be banned, even though our laws do not constrain other nations, and more than likely cloning a human will happen in the future anyway?
3. Is it possible that human cloning can be thought of as another form of human procreation, which many consider a human right?
4. Even if you oppose cloning a human, are you opposed to cloning body organs such as skin, hearts, and kidneys?

Although the question of cloning had been discussed since the early 1960s, no real strategies, helpful insights, or provisional tactical decisions had been made to assist with the current reality. This seeming inability to address novel biological developments may represent a real flaw in bioethical reasoning.

Our ability to clone a human is acclaimed at both ends of the spectrum. There are those who see it as the final attack on the family and envision the beginning of the apocalypse, and others who shrug and wondered what the fuss is about. It is difficult to even enumerate all the possible uses that humans might find for the technology. Should the technology be used to:

- Replace a beloved child who died an untimely death?
- Provide a child following the untimely loss of a beloved spouse?
- Provide replacement parts for an individual over a lifetime?
- Provide children to infertile or gay couples?
- Promote certain types of humans such as a team of Michael Jordans?
- Continue great humans such as Mother Teresa?
- Continue the individual who wants this limited form of immortality?

Should the new technology be argued as a reproductive rights issue? Is cloning so different from other forms of reproduction as to fall outside the constitutional guarantees of procreative liberty? There are very few social constraints on personal reproduction. There appears to be all sorts of unwise, unregulated, and unrestrained procreation taking place, with even the most irresponsible people being allowed to have children. If this is the correct position regarding reproductive rights, why say no to cloning? If anything goes in reproductive rights, then anything goes, and perhaps that should include cloning.

Yet some argue that we have been morally lazy in the reproductive rights area, and the cloning issue may be the catalyst that provides the impetus to focus again on the limits of procreative liberty. Is there a legitimate place in the social community for agreements in regard to the who and how of procreation and the raising of children?

In regard to the cloning of a human baby, the President's Council on Bioethics[15] is in clear opposition, holding that the process would violate the principles of the ethics of human research. There is a high rate of morbidity and mortality in the cloning of other mammals. Cloning to produce a child would be equally dangerous and unsafe, with a high percentage of failures, and as such, attempts to produce a child would be highly unethical. What is to be done with the almost successes? The council feels that even conducting experiments in an effort to make the cloning of a human safer would itself be an unacceptable violation of the norms of research ethics. So there seems to be no ethical way to try to discover whether cloning-to-produce-children can become safe, now or in the future. Beyond those safety issues, the Council holds that cloning-to-produce-children would be a radically new form of human procreation that leads to concerns about: (1) problems of identity and individuality; (2) concerns regarding manufacture; (3) the prospect of a new eugenics; (4) troubled family relations; and (5) effects on the family.

It is possible that as a species, we may back away from cloning full humans, but cloning as a technology will proceed. It is quite likely that we will master our control of the genes enough to enable us to clone distinct body parts for transplantation. In that these parts will be genetically identical to the rest of the patient's body, the problem with rejection will be resolved.

In the interim, it appears that animals will be more radically altered in our quest for body parts to assist in the human organ shortage. There are still technical problems with the transfer of animal viruses to humans and the refining of immune response suppression, but both problems can be resolved. It is not a great leap in expectation to believe that xenotransplantation will become commonplace.

The alteration of agricultural products and animals for human benefit will surely be a key part of our future. It is likely that we will reengineer various types of pharmaceutical foodstuffs like corn and bananas to replace some medicines. Whole new farm factories may develop that produce high-quality proteins. We now have created monkeys that glow in the dark and placed human genes in pigs.[16]

In his 2013 book, *Creation: How Science Is Reinventing Life Itself*, Adam Rutherford explains how four billion years of evolution has worked at the cellular level, and then introduces us to current scientists reengineering existing cells. It is a matter of "copying, adapting, and transforming what has come before." Goats that produce spider's silk in their milk and brewer's yeast that generate diesel are just two of the many useful products that are available through reengineering.[17]

Could we in the future create a potato that tastes like pork and has human genes, giving us the option of being both a vegetarian and cannibal at the same time? For many Americans, the European ban on genetically altered foodstuffs seems both self-serving and irrational. However, when one contemplates what we could do, who knows? In light of future possibilities consider the following three quotes.

- Peter Goodfellow, geneticist: *"I'd like to believe you can't do science if you're a really evil person, but it's probably a romantic view."*
- Francis Crick, biologist: *"The development of biology is going to destroy to some extent our traditional grounds for ethical beliefs, and it is not easy to see what to put in their place."*
- Bryan Appleyard, author: *"Between the scientist and the application of his work stands society."*

Is this a time to rush forward, or pause to consider what input we should all have in these decisions? After all *Frankenstein* is a cautionary tale in regard to the unintended consequences of leaving the choice to scientists.

STEM CELL RESEARCH

Stem cell research is another area that both gains from and suffers from the attempts to weld together a cohesive social policy within the glare of public debate and politics. These amazing cells are the topic of heated debate.

In August 2001, President Bush attempted a compromise: scientists could apply for federal funding only for research utilizing 78 existing stem cell lines. (A *stem cell line* is a family of constantly dividing cells, the product of a single embryo.) Since the announcement, the true number of available and suitable lines appears to be much smaller than the higher number. These existing lines were created using now-obsolete techniques and are considered less suitable than some of the newer lines. However, they appear adequate for research into the switching mechanisms, even if they would not be suitable for future therapeutic applications. The restrictions do not hamper the use of private funds for the other lines, only federal funds. In effect, what President Bush did was to draw a line with federal funding. In his compromise, he managed to irritate just about everyone. Because embryos are destroyed in the process, he went beyond many of the more fundamental of his political base, and by not swinging open the door to all the lines (both present and future) with federal funding, he left himself open for criticism that he was keeping patients from getting the miraculous cures that were promised.

In 2009, President Obama removed limits on federal funding of stem cell research and called for the National Institutes of Health to produce new guidelines covering the process within 120 days. Advocates believe this will lead to therapies that will revolutionize medicine while critics condemn the research as immoral "Frankenscience."[18]

Human embryonic **stem cells** are the building blocks of life. They are like blank slates, potentially capable of becoming any cell in the body. Early in pregnancy, they begin to differentiate into all of the body's specialized tissues and organs.[19] The dilemma in regard to this research is tied to the word *embryo*. Human life begins with the embryo, which grows into a fetus, then an infant, then a child, then an adult. One can stand on pretty firm moral ground and argue against the justification of killing an adult, child, or infant for research purposes, the aim of which is to provide body parts for other human beings. We then are back to whether the embryo should have the same moral protections.

The argument from this duty-oriented position is that moral tradition teaches that we must treat every living member of the human species, including embryos, as a human person with fundamental rights, including the right to life. Some have argued that if a clear line is not drawn, then other populations, such as those in persistent vegetative states, could be at risk in the future. If you draw the line at the moment of conception, then because we are all of equal dignity, we are not at each other's disposal. Does the use of human embryos as raw materials for biotechnology undermine the value of all human life?

Yet there are problems because as humans, we often want to be on both sides of an argument depending on our current desires. When confronted with personal infertility, even those who argue that the line should be drawn at the moment of conception will often rejoice in the prospect of a process that would bring them a child, even when numerous embryos are created, then frozen, rated for their quality, discarded if they hold genetic defects, or are thawed and discarded. None of these practices would be acceptable if we were dealing with adult humans. What is to be done with the hundreds of thousands of embryos, each the size of a pinhead, that are stored in cylinders filled with liquid nitrogen at more than 430 fertility clinics in across the United States? If being thawed and destroyed is truly the fate of these excess embryos, why not use them for biotechnological research?

This forms the basis for a second line of reasoning in regard to stem cell research, which recognizes that investing in science and technology is always a consideration of risks and benefits. Biological research has extended human life and improved its quality. Yet every step forward has exacted a toll in harms and risks. Scientists using this form of utilitarian reasoning would argue that the benefits from stem cell research are of such great magnitude that the required destruction of human embryos in the process, especially ones that are to be discarded anyway, is permissible. Again, imagine the benefits that humanity will gain from a new specialty of **regenerative medicine** that is focused on growing specialized tissues for spinal cord injuries, diabetes, cancer, multiple sclerosis, Parkinson's disease, and many other currently unthought-of applications.

IN THE NEWS

Made to Order Organs

Kidney disease is one of the top ten causes of death in the United States. Once the kidneys fail, dialysis or a kidney transplant is required. According to the National Kidney Foundation in 2014, nearly 5,000 patients died while on the transplant list. Recently researchers have grown an artificial kidney raising hopes that in the future these organs could one day be manufactured to order and solve the organ shortage.[20]

Using chemicals, the researchers stripped a rat kidney of its original cells, leaving only a collagen scaffold. This structure was then bathed in stem cells and neonatal kidney cells, which

Continues

Made to Order Organs (cont.)

grafted to the scaffold and began to grow new kidney tissue. When transplanted into a rat, the new kidney began to filter and produce urine, although less efficiently than a regular organ. Scientists hope that the process can be improved and scaled to human-size grafts. In theory the same technique could be used for to produce livers and hearts. One of the great benefits would be that the organs produced would be identical to the patient's own cells, removing the problem of immune system rejection.

Below are some statistics on organ transplants:[21]

- There are currently 121,678 waiting for lifesaving organ transplants in the United States. Of these, approximately 100,791 are awaiting kidney transplants (data from 1/11/2016).
- The median wait time for an individual's first kidney transplant is 3.6 years and can vary depending on health, compatibility, and availability of organs.
- In 2014, 17,105 kidney transplants took place in the United States. Of these, 11,570 came from deceased donors and 5,535 came from living donors.

On average:

- Over 3,000 new patients are added to the kidney waiting list each month.
- Twelve people die each day while waiting for a life-saving kidney transplant.
- Every 14 minutes someone is added to the kidney transplant list.
- In 2014, 4,270 patients died while waiting for a kidney transplant. Another, 3,617 people became too sick to receive a kidney transplant.

The transformation of medicine has just begun, but is already producing startling results. Recently researchers created the equivalent of an ink jet "printer" that uses tubes of cells instead of an ink cartridge to create thin layers of skin. It is hoped that this technique will help burn victims heal using skin produced from their own cells. Starting with a single donor skin cell, a team of bioengineers have grown sheets of tissue, rolled them into straw-like shapes to form arteries and veins, and successfully implanted them in three kidney patients to improve their ability to undergo kidney dialysis. The new vessels could eventually replace the expensive artificial shunts used in heart surgery. A herd of modified goats in Massachusetts is producing an otherwise costly anti-clotting drug free of charge—in their milk.[22] The key to this rapidly evolving understanding of life itself, has been the sequencing of the human genome and advances in stem cell research. But the final application of stem cell research may in fact not be therapeutic applications at all, but an increased knowledge of how the human body works. It is important to keep in mind where we are in the science of this issue, because when politics enters the process, we are confronted by those who would take complicated science and moral issues and reduce them to pro and con bumper sticker slogans.

HUMAN ENHANCEMENT

Consider the case of a young boy who was 4-feet-1 inch tall and a full foot shorter than any of his classmates. An endocrinologist prescribed Human Growth Hormone (HGH) and he grew to 5-feet-7 inches by the age of 16. But his mother would like him to be above average in height and is battling the insurance company to continue funding his expensive injections.[23] Now, 5-foot-7 inches may not be tall, but it is not short either, and he is otherwise healthy. Should the mother have her way? Is human enhancement, beyond that needed to restore health, acceptable therapy? It is one thing to remove burn scars to the point they are invisible, and quite another to make you into an Adonis.

In addition to modifications to appearance, advancements are being made in the realm of neurological enhancements. Recently, "a major breakthrough was announced as scientists were able to manipulate the brain circuitry in rats to both erase and restore memories." One leading investigator was quoted as saying, "We were playing with memory like a yo-yo." It is hoped that the research will lead to new treatments to help reverse memory loss.[24]

But let us imagine that in fact the research progresses to the point where human memories could be erased and new ones inserted. One could see the great benefit of erasing memories, as many have suffered traumatic events that plague their dreams and interfere with their mental health. It is estimated that as many as twenty-two veterans die each day from suicide. Could this be countered by erasing the memories associated with post-traumatic stress disorder? That would certainly be acceptable therapy, but what of the flip side, what if we could implant memories of events that never occurred? How many of us, for whom high school was a nightmare, would like to remember it as the time when you were wonderfully popular? It is difficult to avoid the treatment/enhancement distinction. Are there medical limits to human enhancement, when the requests go beyond our normal role as healers?

This is an important question as we consider the ideas of post humanism sometimes referred to as transhumanism. There are some within the camp of philosophers, including Donna Haraway,[25] Judith Halberstam,[26] and Francis Fukuyama,[27] who feel that we should not view the present situation of rapid scientific advancement as a cautionary tale but rather as a time to embrace the technology and possibilities of genetic engineering. While it is generally believed that human evolution is largely over given that medicine undermines natural selection, posthumanists believe that evolution is far from over. Natural selection in the biological realm is probably finished, but we humans will keep changing as a result of our interaction with the world.

Human nature is not fixed. In fact, if we consider that humans are defined anthropologically as the tool-using animal, as tools evolve, so will humans. Humans in the past changed with the transitions from horse-pulled carts to trains to personal automobiles to planes to spacecraft, or farming tools to industrial machines to computers. It is not simply human-machine interaction that changes humans; human-animal interaction is equally important. We began evolving transhumanistically when we started riding horses and domesticating dogs. However, none of this was clear until the advent of modern medical technology. Genetic manipulation, heart pacemakers, surrogacy, transplants, test tube babies, human interaction with computers, artificial intelligence, exoskeletons, transportation vehicles, and all other inventions break down the boundary of the human body.

As we become ever more intertwined with technology, we find ourselves becoming something more than human—something "posthuman." Posthumans are also likely to welcome nonhumans to the posthuman future. Artificial intelligence, robots, created species, chimeras (species mixes), and a global Internet consciousness are all possible coinhabitants of the future.

The key to **posthumanism** is that the "cyborg" existence is not to be resisted. Some liken our normal form as merely computers made of meat, so melding biological computers (the human brain) with silicon brains (computers) seems rational. Posthumanists do not question the ethics of contemporary uses of technology, or at least they do not see these developments as necessarily negative. In fact, the prospect of greater interdependence is something they find exciting and appealing. Posthumanists embrace the future as they find the problems of human suffering, physical limitation and death to be unacceptable. Theirs is a technopian vision of a pain-free, unlimited, eternal humanity. They are not oblivious to the dangers that technology raises, but they regard dangerous technology as an ongoing management issue.

The posthumanist position may be naively positive toward the future, but it is a refreshing counterpoint view to luddism. The future is coming whether we like it or not. We saw with cloning that even banning a technology will not stop its development. Nevertheless, posthumanism seems too willing to overlook the ethical issues raised by new technologies. There is ample room for compromise, however, since posthumanism can easily add ethical arguments without contradicting its central premises. One could imagine that if the posthumanist view is correct, ethical considerations in the future will still rely on duty, utilitarian, and virtue models to examine problems; however, concepts such as natural rights and human rights may become obsolete. We may, for example, still seek to maximize happiness, but the being whose happiness is to be maximized may be very different from the human of John Stuart Mill's time.

The ethical worries about issues such as cloning, stem cell research, genetic engineering, and posthumanism have as much to do with the vague fear that as humans we are "playing God" and are not up to the task. Some theological viewpoints hold that the mere possession of such profound knowledge is immoral; only God should have such power. The idea is that the attempt to gain this level of knowledge is hubris, or excessive pride. It is suggested that we leave such things to God and concern ourselves with more mundane tasks.

Although posthumanism and transhumanism may seem distant possibilities, we are on the cusp of change; advancements currently underway will change the quality of our lives, probably extend our lives, and definitely make the lives of our children healthier and longer than ever. In the near future we may see the end of cancer and deaths from heart disease.[28]

We live in a time of amazing medical breakthroughs. Through the use of microchip implants, people who become blind will see again. Genetic diseases may no longer exist. Currently, researchers use DNA therapy to vaccinate people against gene-specific diseases. Organs will be replaced on demand. Scientists, using the patient's own tissue or synthetic materials, will grow a replacement in a laboratory. Using microchip technology, we can repair brains. The advancements in neurological enhancements offer great hope for a better life for those who've had a stroke, or suffer from neurological diseases. The same technology may also offer the possible expansion of brain use for everyone. We may soon be able to create babies who are smarter, more talented, more beautiful, and disease free. Using nanotechnology, we may discover the "fountain of youth." Working on an atomic or molecular scale we can create subatomic cellular repair robots designed to enter our blood stream and seek out cellular damage caused by the aging process. In the future, we may take a pill and watch ourselves grow younger.

Over the past hundred years, we have doubled our life expectancy, at least in the developed world. Will our biological road map let us do that again? Some hold that aging itself may be entirely a genetic process, which could be manipulated. Is immortality an option? Would that even be beneficial? Perhaps the better and more ecologically acceptable route would be to live disease free and well for 85 years and die quickly in our sleep after a day in which we made a hole in one on the golf course. For most of us, the option of a longer life is not acceptable if it means a longer period of helpless dependency.

One study finds that if current health trends continue, more than half of all babies born in industrialized nations since the year 2000 will live to an age of 100. In the United States the expectancy for kids born today is likely to rise to 104. The bad news is that societies with tens of millions of people in their 80s and 90s will face unprecedented demands on their health care, retirement systems, and social structure.

Consider the following:

- Some of these changes are based on adapting technology to enhance humans, while others are changes in the germ line itself, which can permanently change humanity. Is this a material difference? Which is more ethically appropriate, a cyborg existence where a human is enhanced by technology, or an alteration in the human germ line, which potentially can change humanity itself? Do you favor one and not the other? Explain your answer.

- Can the concept of human rights be extended to include post humans?
- How will life change if the world's population grows because we are living longer and healthier?
- Will these changes be available to the whole world, or only the fortunate few?

CONCLUSION

The advances in scientific expertise bring with them moral dilemmas. Genetic research offers great promise; we may soon be able to cure many of the genetically determined diseases and predispositions to disease. We may even be able to improve upon Mother Nature. The question is whether humankind has the wisdom to utilize this knowledge for good without violating moral rules. Only time will tell. Genetic screening will allow parents to know whether their offspring will be afflicted with disease, but in some cases this does nothing more than begin the misery sooner. Prenatal genetic testing will give parents the choice to terminate pregnancies that will lead to severely ill or disabled infants. Genetic testing may also justify discrimination in the minds of many. Eugenics as a state policy is unlikely and will be a long time coming, if ever, but it is fraught with the possibility that charlatans will make such proposals. The human genome project will rank among humankind's greatest achievements, and by itself it presents no real moral difficulty; but the application of the knowledge may be more than human wisdom can handle. Recombinant DNA may be the most dangerous as it puts us in the position of creators of whole species that may or may not coexist with humanity and the rest of the natural world. In spite of the dangers, we will proceed, as we should. We may not turn away from the pursuit of knowledge even if some would misuse it.

KEY CONCEPTS

- A new and vast horizon of possibilities is opening up as the result of the ongoing biological revolution. Choices will need to be made that will affect the very concept of what we mean when we say we are human.
- The opportunities afforded by issues such as cloning, and genetic engineering fit well within the legend of Faust. Shall we rush forward on all fronts, seeking new knowledge and applying new applications of that knowledge, or accept that in some areas, humans should limit the quest and application of knowledge?

- This chapter deals with issues that can be considered small ethics—issues such as the need to protect the confidentiality of genetic profiles from insurance and employers—and large ethics, such as eugenics, where we determine what and who we are going to be in the future.
- It is unclear whether the current tools for evaluating ethical problems are capable of dealing with the unique and novel dilemmas that we are beginning to face.
- Human embryonic stem cells are the building blocks of life. Early in pregnancy, they begin to differentiate into all of the body's specialized tissues and organs.
- Most scientists working with embryonic stem cells justify the destruction of human embryos in the process by using a form of utilitarian reasoning, where the potential benefit is greater than the harm.
- Embryonic stem cell research with the resulting destruction of embryos creates a moral problem for those who hold that human life begins at the moment of conception. If this is true, then destroying embryos can be likened to killing humans and using them as raw material for biotechnical research.
- We are the only extant species of the genus *Homo*. The biological revolution may provide us opportunities to expand the species at the very least; it will provide us the opportunity to prove whether we deserve the title *Homo sapiens* (man of wisdom or thinking man).

REVIEW EXERCISES

A. If it became a general practice to abort genetically impaired infants, what would be the likely effect upon genetically impaired infants who are not aborted? Is this a reason to restrict abortions done for this reason?

B. Currently we are able to detect the sex of the child very early in pregnancy, and we are working on the ability to also select the sex. Assuming such a practice could be done safely, is it morally defensible? What moral difference could it make whether parents have a male or female? Would you want to be able to choose the sex of your children? Would you have wanted your parents to have had this power?

C. There currently are efforts to investigate whether criminal behavior is genetically determined. Aside from the scientific implausibility of all criminal behavior being explained genetically, should someone be discriminated against if his genetic makeup showed him susceptible to such behavior, even prior to actually committing a crime?

D. Most work in genetic engineering has been focused on making people better than nature and chance would make them. What would you think of a eugenics policy of producing humans who were inferior to other humans for the purpose of manual labor?

E. Given that the insurance industry is in the business of assessing risks, is it unfair for it to discriminate against individuals found to have a genetic predisposition to, say, mental health problems?

F. Imagine that you have just found out that you have Huntington's disease. You have two children; do you tell them that there is a fifty-fifty chance that the offspring of someone with Huntington's will have it as well? What if you know that they are not planning to have children? What if they are?

G. Imagine that your parents could have had you genetically altered to be better looking, as athletic as a professional athlete, and with genius-level intelligence without altering your basic personality. Would you have preferred that they had done so? If the technology existed, would parents be morally bound to have you genetically altered for the better? What if all the other parents did so except for yours?

H. Can you think of a case where humankind has acquired knowledge without using that knowledge? If not, does that mean we should refrain from continuing the genomic research?

I. Compare the character of Dr. Faustus with the character of Dr. Frankenstein. Does this help us illuminate the dilemmas surrounding genetic engineering?

J. When is the appropriate time to discuss ethical dilemmas of the future? Do we wait until we are actually faced with the problem, or do we try to anticipate it? Anticipating the problem gives us longer to try to develop solutions, but it may also be a waste of time if the future does not play out as anticipated. Compare other scientific developments that have led to moral problems, such as atomic science, to recent developments in genetic technology.

K. Should parents be obligated to use gene therapy if it were available to fix any genetic abnormalities in their children?

L. Imagine a scenario in which a headless duplicate was cloned for each person born to serve as a source for body parts as needed by the original later in life.

1. Would such a procedure be morally problematic?
2. Would it be more ethically acceptable if animals were genetically altered to provide humans with spare organs?

M. The idea that the exploration of science is its own end is interesting and challenging to bioethical reasoning. To what extent should society restrain the efforts of scientists? What place do ethical considerations have in the decisions of science?