



CHAPTER 4

Controlling Our Genetic Futures

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Controlling Our Genetic Futures

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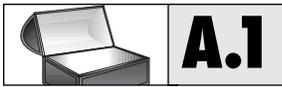
CHAPTER 4

**Controlling Our
Genetic Futures**

SECTION A

**Biotechnology:
Panacea or
Pandora's
Box?**





Promise & Perils of Biotechnology: Genetic Testing

(A Video Presentation)

WHEN YOU SIMULATED a genetic screening test in exercise 3.E, you probably began to appreciate how much impact the results of such a test can have on an affected family. In this unit you will view a videotape that elaborates on this theme, using two case studies.

The first case study concerns a young woman, Jennifer Jones who has decided that she wants to know whether she has inherited from her father the dominant mutation that causes Huntington's disease. Even though Jennifer realizes that there is no way she can protect herself from this dread disease if she has inherited her father's mutant allele, she has decided that she must know the answer, so that she can begin to plan the rest of her life accordingly.

The second case study is of a very different sort. It deals with a mother and child who share a mutation that profoundly increases their risk of heart disease. But by learning that they have the mutant condition early in life, Lily Ann and Lora Sholer are able to change their lifestyle, so as to reduce greatly their levels of risk.

Work Sheet for

Promise & Perils of Biotechnology: Genetic Testing

BEFORE VIEWING THE video, answer the following three questions:

1. What does genetic testing usually involve? _____

2. Who needs genetic testing? _____

3. What are some of the reasons for and against undergoing a genetic test?

For: _____

Against: _____

After viewing the video, answer the remaining questions:

4. Now that you have seen the video, would you answer any of the above questions differently? Explain.

5. If you had been in the same situation that Jennifer Jones was in, would you have wanted to be tested as she was? _____ Why or why not?



Name _____

Date _____ Hour _____

6. If you had taken the test and learned that you had the gene for Huntington's disease, how would you have used the information?

7. If you had been in the same situation that Lily Ann Sholer was, would you have wanted to be tested as she was? _____ Why or why not?

8. If you had been in the same situation that Lily Ann Sholer was, would you have wanted your daughter to be tested also? _____ Why or why not?

9. Is there anything that you think Lily Ann and her daughter should do in addition to eating a low-fat, high-fiber diet and taking their medicine in order to lower their chances of having a heart attack?

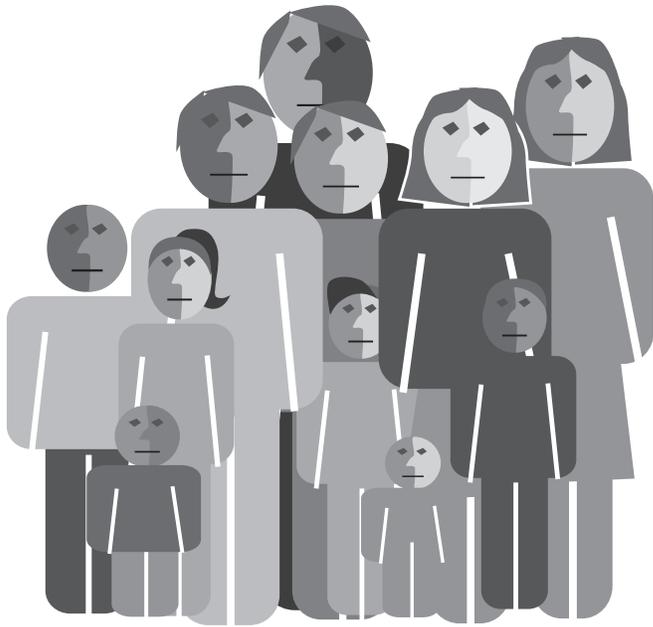
10. Do you think it is fair that Lily Ann can not get insurance for Lora because of Lora's genetic constitution? Explain:

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SECTION B

**Resolving
Genetic Testing
Issues:
An Introduction
to Group
Decision Making**



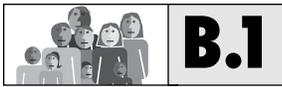
A Value-Based Approach to Group Decision-Making

SOONER OR LATER, NEARLY every human being comes to realize that there are certain things that it would be possible to do that it would be ‘wrong’ for them to do.

Ethics and morals both deal with values such as right/wrong, good/bad, should/should not. The words ethics and morals were originally considered to be completely synonymous, with the only difference being that ethics is derived from a Greek root meaning ‘character,’ whereas morals is derived from a Latin root meaning ‘manners.’ Although some dictionaries, as well as some experts who work in the field*, still fail to make a significant distinction between ethics and morals, in common usage the terms have come to be differentiated from one another rather sharply, in at least two important ways:

- In everyday usage, the terms morals and morality are often given a narrow, sexual connotation that is hardly ever associated with the terms ethics or ethical. Most people would agree that the statement that someone is “a person of the highest moral standards” implies that he or she would neither be guilty of sexual misconduct, nor would condone sexual misconduct on the part of others. On the other hand, most people would not interpret the statement that someone is “a person of the highest ethical standards” as saying anything at all about that person’s sexual attitudes. Rather, they would probably interpret it to mean that in judging the appropriateness of any particular course of action that person would surely disregard matters of self-interest, personal preference and momentary emotions, and would consider instead matters such as individual rights, personal dignity, and the importance of trying to achieve uniform justice for all.
- A second distinction in the way that these terms are commonly used is that morality tends to be more closely connected to the particular set of religious beliefs to which an individual subscribes. Thus, for example, the declaration that a particular action would be immoral often implies that the action would be inconsistent with the religious values of the person making the declaration. In contrast, the declaration that an action would be unethical rarely carries any such connotation. Rather, it implies that the action is one that is so contrary to widely shared values, that it probably would be considered wrong by all reasonable people who gave the matter serious thought – independent of their religious affiliations (or lack thereof).

* It is interesting to note, however, that experts who resist making any formal distinction between ethics and morality almost always identify themselves as ethicists, rather than as moralists.



Experience indicates that a group of individuals from diverse backgrounds will find it much more profitable to discuss difficult problems involving matters of right and wrong if they proceed in an ethical, rather than a moralistic framework. It is next to impossible for individuals who come from different religious and cultural backgrounds to agree on an appropriate course of action in a difficult situation if all of them merely shout out opinions that are based on their own religious doctrines or ‘gut feelings.’ On the other hand, agreement is more likely to be achieved if all members of the group try to evaluate calmly how each possible alternative course of action would relate to certain human values that they agree in advance are really important – which is the essence of an ethical approach.

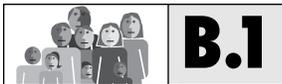
DEVELOPING A SET OF SHARED VALUES

Before you and your classmates will be able to discuss various difficult and controversial issues raised by modern genetics in an ethical framework, you will need to develop a list of important values that you all agree on. Some that you might consider are listed below.

- Respecting the rights and dignity of all others
- Treating each person as an individual, rather than as just another member of some particular group
- Promoting the welfare of those who are less capable of protecting their own interests than you are
- Placing the interests of one’s own family above the interests of all others
- Promoting understanding of human nature and of the world in which we live
- Dealing with others as you would want them deal with you
- Protecting others from unnecessary harm or pain
- Telling the truth
- Cheering for the hometown or school team
- Allowing all persons who are able to do so to make the important choices that will affect their lives
- Defending the right of people to be fully informed before making such choices
- Lending a helping hand to those who are less privileged than oneself
- Assuring that all people are treated fairly and equitably

This list is not intended to be either complete, or arranged in order of importance. You and your classmates will need to discuss and revise it. You might choose to reword some items on the list, combine some of them, add or delete others, and evaluate the relative importance of all entries on your final list. Other shared values may occur to you as you consider particular ethical problems.

Two work sheets are provided. The first one is for you to use to record your own ideas about how the above list should be modified. The second one is to record the list that you and your class agreed upon as a result of your classroom discussion.



ONE APPROACH TO ETHICAL DECISION MAKING

One way to proceed with any exercise in ethical decision making would be as follows:

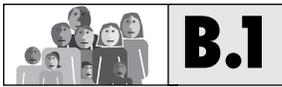
- Define the ethical dilemma(s), or issue(s), that the case in question highlights. Be sure that there is agreement about the nature of the problem.
- Identify all of the individuals and/or institutions (usually called “stakeholders”) that are likely to be affected in a substantial way by any course of action that is eventually decided upon.
- List as many possible alternative courses of action as seem appropriate for the case being considered.
- Identify how each of the alternative courses of action would affect each of the stakeholders.
- Identify how each of these effects might sustain or violate one or another of your shared values.
- If you find that some course of action would create a conflict between two of your shared values (as will often be the case) try to evaluate the relative importance of the positive versus the negative effects.
- Based on the extent to which they sustain or violate various of your shared values, order the alternative courses of action from most desirable to least desirable.

Then place each of the alternative courses of action that you have considered in one of the four ethical categories that are listed next.

FOUR ETHICAL CATEGORIES OF POTENTIAL ACTIONS

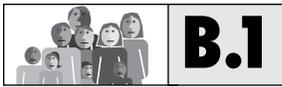
Ethicists generally agree that it is useful to distinguish the following four types of actions:

1. Actions that are ethically required. (Example: providing one’s children with the basic needs of life, such as food, clothing and shelter – to the extent that one is able to do so.)
2. Actions that are ethically desirable, but not ethically required. (Example: providing one’s children with the assortment of foods that are most likely to promote their long-term health.)
3. Actions that are ethically undesirable, but not ethically unacceptable. (Example: permitting one’s children to eat enough candy and ‘junk foods’ to potentially endanger their health.)
4. Actions that are ethically unacceptable. (Example: providing one’s children with drugs or alcohol, in hopes of addicting them.)



Another important point on which there is widespread agreement is the following: A judgment that some particular action is ethically desirable (that is, that it falls in category 2) does not provide adequate justification for trying to coerce another individual to act in that manner. Similarly, a judgment that some particular action is ethically undesirable (that is, that it falls in category 3) does not provide adequate justification for trying to forcibly prevent another individual from acting in that manner.

Try to use this kind of framework in considering the case studies in sections C.1 and C.2.



Name _____

Date _____ Hour _____

WORK SHEET FOR DEVELOPING A SET OF SHARED VALUES

A. My Personal List

Consider each of the items in the list below. If you think an item does not belong on the list, cross it out. If you think an item should be worded differently, write your preferred version in the space provided. If you think two items could be combined, cross one out and next to the other write your proposed combined version. If you think there are items that should be on the list but are not, add them on the blank lines at the bottom. Finally, when you think your list is complete put a number 1 to the left of the item on your list that you consider the most important, number 2 next to the second most important, and so on.

Respecting the rights and dignity of all others _____

Treating each person as an individual, rather than as just another member of some particular group

Promoting the welfare of those who are less capable of protecting their own interests than you are

Placing the interests of one's own family above the interests of all others

Promoting understanding of human nature and of the world in which we live

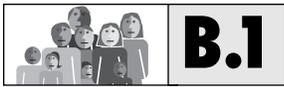
Dealing with others as you would want them deal with you _____

Protecting others from unnecessary harm or pain _____

Telling the truth _____

Cheering for the hometown or school team _____

Allowing all persons who are able to do so to make the important choices that will affect their lives



Name _____

Date _____ Hour _____

Defending the right of people to be fully informed before making such choices

Lending a helping hand to those who are less privileged than oneself

Assuring that all people are treated fairly and equitably

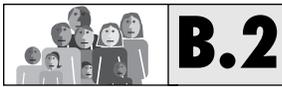
New Genetic Tests Lead to Difficult New Questions

THE PROGRESS THAT HAS been made in developing genetic screening tests recently has been truly staggering, and has raised an number of important issues that will need to be faced in coming years. Consider the developments that have occurred just within your lifetime. At about the time that you were born:

- only a few hundred human diseases were recognized as having a significant genetic component, whereas we now know that more than 4,000 do;
- biologists understood the molecular basis of no more than a half dozen such diseases, but now the molecular basis of several additional diseases is discovered nearly every month;
- not a single DNA sequence had ever been patented, but by now patents have been granted or are pending for more than 500,000 DNA sequences – including 150,000 gene fragments from humans;
- determining the sequence of base pairs in a DNA molecule was so difficult that only a few genes had been sequenced in their entirety, but by now anyone with access to the web can look up the sequence of nearly all 3,000,000,000 base pairs that constitute a human genome;
- there were only a few genetic diseases for which carriers could be detected by molecular methods, but soon it may be possible to determine an individual's carrier status with respect to hundreds of genetic diseases at once, starting with only a single drop of blood.

As the video *Promise & Perils of Biotechnology: Genetic Testing* implied, many of these changes have come about because of the Human Genome Project (HGP). The HGP was launched in 1990 with the goal of determining the sequence and the function of every single gene in the human genome. Progress in the sequencing activity was much faster than originally anticipated. Thus, in the year 2000 HGP scientists announced that they had completed a 'first draft' version of the sequence, years ahead of schedule. During this ten-year period, dozens of disease genes were identified and sequenced. Sadly, however, progress in treatment of genetic diseases has been proceeding at a pace that is orders of magnitude slower than the pace of detecting and sequencing the genes that cause those diseases. As a result, it is now clear that for the foreseeable future biomedical scientists will be able to detect far more genetic diseases than they will be able to cure. This raises many serious and difficult questions about how to use our these abilities to perform genetic screening.

A few of the difficult issues we might wish to address on a very personal level include: How much do I really want to know about my own genetic constitution or that of my



potential children? Would I want to know that I am certain to suffer a painful, deadly disease 10 or 20 years from now, if no one has any idea how to prevent or cure that disease? Would I want to know that my unborn child has inherited such a condition from me? Do I have the right to take a chance of giving birth to a seriously ill or retarded child if there is some way that I could avoid doing so?

Once we think about it for a moment, however, we will realize that we will not necessarily be free to make all of the important decisions about our genetic health ourselves. For example: if my doctor establishes that I have a genetic condition that will later lead to some serious disease, will she be able keep that information confidential, so that I will be free to make a private decision about how to use the information? Or does she have an obligation to share the information with my insurance company? my employer? the government? my relatives?

Some of the questions we might ask on a slightly broader scale are: What obligation do members of the present generation have as a group to future generations? Should states require that all persons seeking a marriage license be tested to determine whether their children might have a serious genetic disease (as most states now require them to be tested for certain infectious diseases)? Should insurance companies be allowed to include genetic screening in the medical exams that they now require before issuing an insurance policy? If so, should there be any limits on what they can test for, or how they can use the information?

Then there are questions of an even broader nature that clearly should be addressed, such as the following: Should we as a society try to assure that our new genetic knowledge will be used fairly, to decrease the suffering of rich and poor alike? Should we, or can we, do anything to assure that such knowledge is not used just to enrich companies that develop genetic tests, and to benefit only those who are wealthy enough to afford the benefits, thereby increasing the disparity between rich and poor?

These questions call for several quite different kinds of decisions. Some are strictly matters of personal preference (“how much do I want to know...”). Others involve legal issues that ultimately may require consideration by various legislative bodies and courts (“should insurance companies be allowed to...”). But some of the most important ones involve ethical issues (“do we have an ethical obligation to...”).

Our society will face many questions of the latter type in the next few years. Experience indicates that such issues have the potential to generate intense controversies and bitter divisions in society. If we wish to avoid such divisiveness, we will all need to learn how to deal with such issues in a thoughtful, respectful and non-confrontational manner.

CHAPTER 4

**Controlling Our
Genetic Futures**



SECTION C

**Genetic
Testing:
Two Case
Studies**

Roger Patton's Dilemma

ROGER PATTON IS A first-year biology teacher. He and his wife were married right after they graduated from college. In Roger's first year of teaching, he and his wife, Carey, decided to start a family. Carey became pregnant within a few months. Both Roger and Carey are 24.

Only a few weeks later, however, while Roger was preparing to teach the genetics section of his Biology course, he read a pamphlet that made him realize that the increasingly strange behavior his father had been exhibiting in recent months might indicate that his dad was in the early stages of Huntington's disease.

Among the things that Roger read were the following:

“Huntington's disease (HD) is a progressive disorder involving degeneration of nerve cells in the cerebrum (the largest portion of the brain). Symptoms usually do not appear until somewhere between the ages of 35 and 50. The disease is characterized by progressive personality changes, including depression, and progressive loss of cognitive functions, such as the ability to calculate, form judgments and speak coherently. Abnormal facial and body movements, including quick, jerking movements of the arms and legs, become progressively more frequent and stronger. These uncontrollable movements account for the alternative name for the disease which is Huntington's chorea (chorea means dance).

“HD is an autosomal dominant disorder with complete penetrance that is caused by a mutant gene on chromosome 4. The term dominant disorder means that it takes only one copy of the mutant allele to cause disease symptoms; the term complete penetrance refers to the fact that (in contrast to many other genetic diseases) everyone who inherits the mutant allele develops symptoms of the disease (unless they die prematurely from some other cause). Taken together, these facts mean that each child of an affected individual has a one-in-two chance of being affected also. No way is known of preventing HD or ameliorating its symptoms; it is eventually fatal.”

Suddenly, genetic testing took on a whole new meaning for Roger, and he immediately decided to have himself tested to see if he had inherited the Huntington's disease allele.

When the results came back, Roger's worst fears were realized: the test indicated clearly that he does have the dreaded HD gene. Now he must think carefully about what to do with the information.



1. Since there is no way to prevent or cure Huntington's disease, should Roger just keep the information to himself and try to live as normal a life as he can, for as long as he can? Or should he at least tell his wife, so that they can decide together whether they want to find out whether Roger has passed the gene on to their unborn child?
2. Should Roger tell his mother what the basis for his father's recent personality change is, and what she has to look forward to over the next few years? And should he inform his father about the grim future he faces? Or should he avoid becoming the messenger of doom, knowing that it is inevitable that both parents will learn the truth soon enough, in some other way?
3. Should Roger tell his sister Joanne, who also is pregnant, that there is a 50-50 chance that she has the Huntington's allele also?
4. Should he do anything to try to prevent his principal from finding out about his condition?
5. Should Roger immediately try to get an insurance policy large enough to protect his family's financial future? Is he obliged to let the insurance company know about his HD status? Can he ask his doctor to withhold such information from the insurance company? Would his doctor be ethically bound to honor – or to ignore – such a request? To forestall this kind of worry, should Roger have been tested in a different city, under a false name?

Fill out the work sheet. Then use the framework outlined in section B.1 to discuss with your classmates the ethical issues that Roger faces. Your goal as a group should be to try to place each of the decisions that Roger might make in one of the four ethical categories listed at the end of section B.1.



Name _____

Date _____ Hour _____

WORK SHEET FOR ROGER PATTON'S DILEMMA

THE NUMBERS ON THE lines below refer to the questions posed on the previous page. Try to put yourself in Roger's shoes as you consider each question. For each question indicate:

- a. Whether you think there any ethical issues involved, and if so what they are;
- b. Which shared value from the list you prepared in section B.1 is most important for Roger to consider with respect to that particular question;
- c. What decision you think Roger will make if he takes that value into consideration adequately.

1. _____

2. _____

3. _____

4. _____

5. _____

Carol and George Face a Tough Decision

GEORGE AND CAROL, both in their mid-thirties, had been married less than a month when Carol's mother called to say that Carol's cousin Muriel had died. When Carol told George about her mother's call, she said, "It's a blessing in a way, because Muriel has had a very painful existence for most of her 13 years, and particularly in the past three years." She went on to tell him that Muriel had a particularly severe case of cystic fibrosis. Although she had two loving and caring parents who worked with her regularly to keep her lungs as free of mucous as possible, and who had provided her with the best medical care available, Muriel had never been able to live a very normal life, and had been hospitalized several times in recent years with severe lung infections. George became very agitated as soon as he heard this, and explained that he had a three-year old cousin with cystic fibrosis. Both of them immediately recognized the implications of this: with a history of cystic fibrosis in both families there was a chance that if they had a child it might have the disease also. Because they were very anxious to start a family, they decided to seek a genetic counselor and be tested.

When the results of the tests came back, the news was not good: Both George and Carol were carriers for the cystic fibrosis allele. This meant, the counselor explained, that there was a one-in-four chance that any child Carol and George had together would be homozygous for the mutant allele, and would have cystic fibrosis. The genetic counselor then went on to list all of the options that they could consider in light of this unhappy news. Included in the list were only two ways that they could have children of their own without having a chance of giving birth to a child with cystic fibrosis. These were (a) Carol could get pregnant in the normal way, have the fetus tested, and then have an abortion if the test indicated that the fetus was homozygous for the cystic fibrosis allele. (b) Carol and George could go to an in vitro fertilization clinic, have several "test-tube" embryos produced, have each of them tested genetically, and have only embryos that were not homozygous for the cystic fibrosis allele implanted in Carol's uterus.

After asking a few more questions, Carol and George thanked the counselor and said goodbye, explaining that they were obviously going to have to think and talk this all over very, very carefully before making any decision about how they wished to proceed.

Fill out the work sheet. Then prepare to discuss the situation with your classmates in an ethical framework of the sort outlined in section B.1. Your goal as a group should be to try to place each of the decisions that George and Carol might make in one of the four ethical categories listed at the end of section B.1.



Name _____

Date _____ Hour _____

WORK SHEET FOR CAROL AND GEORGE FACE A TOUGH DECISION

1. List all of the options that you think the genetic counselor should have suggested that Carol and George should consider in addition to the two that are specifically given on the preceding page.

2. Write a carefully considered opinion regarding the ethical considerations that are raised by options (a) and (b) that are given on the preceding page. Try to justify your opinions in terms of the set of shared values that you and your classmates agreed upon on Work Sheet B.1.B. Then prepare to discuss your opinions with the class.

CHAPTER 4

**Controlling Our
Genetic Futures**

SECTION D

**DNA
in the
News**





DNA in the News

YOUR TEACHER WILL discuss with you how you should now use the news articles on genetic topics that your class has been collecting for the last several weeks.