CHAPTER 2

CONTROVERSIAL ISSUES IN GENE RESEARCH

by Donna M. Brinton, Christine Holten, and Jodi L. Nooyen

Background | **Classroom Applications** | **Internet Resources** | **Appendices**

BACKGROUND

Scientists have recently completed a preliminary "map" of all the genes in the human body. This is also known as the **Human Genome Project** and consists of all the sequences of **DNA** chemical units that tell a **cell** how to behave. This accomplishment has incredible benefits. However, it also raises new, complex issues that society cannot ignore.

This chapter explores the following questions:

What practical results has the Human Genome Project had?

How do these scientific advances benefit us?

What **potential** disadvantages do they have for individuals and society?

The chapter gives an overview of the technologies that have been developed as a direct result of DNA and genetic research. It also gives students the chance to debate the ethical questions surrounding this technology.

Reflecting on the ethical challenges created by genetic research findings, former U.S. President Bill Clinton said, "As we consider how to use new discoveries, we must also not retreat from our oldest and most cherished values.... Increasing knowledge of the **human genome** must never change the basic belief on which our **ethics**, our government, our society are founded. All of us are created equal, entitled to equal treatment under the law." British Prime Minister Tony Blair also discussed the need to use this new technology responsibly: "We cannot resist change, but our job—indeed, our duty—is to make sense of change, to help people through it, to seize the massive opportunities for better health and better quality of life and then, with equal vigor, to minimize the threats such developments pose."

DNA testing: Advantages and Disadvantages

The ongoing project to map the human genome affects all of us in several key areas. The first is **DNA testing.** This subfield of gene research uses tiny human tissue samples of 100–200 cells (for example, blood, hair, saliva) to identify DNA patterns. These samples are used to establish a person's identity, for example, in (1) tests for blood relationships such as parenthood, (2) identification of criminals (rapists, murderers), and (3) proving the innocence of people falsely accused of a crime. In this testing, the DNA pattern of a person's hair, blood or saliva is matched with a similar DNA sample from a second person. For example, when establishing parenthood, DNA from the mother or father is matched with DNA from the fetus or child. When identifying criminals, DNA samples from the crime scene are matched with a suspect's DNA.

Some benefits of DNA testing are clear and unquestioned. It is a key tool in the criminal justice system, helping courts to discover whether a person suspected of committing a crime is guilty or innocent and helping police to find criminals. It has even been used to prove the innocence of criminals on death row many years after a crime was committed. In addition, it is replacing genealogy and family trees as a method for determining ancestry. A famous case is the link that was established between the children of Sally Hemmings, a black slave, and U.S. President Thomas Jefferson. Finally, this test has also been used to establish the identity of dead bodies. One example of this occurred several years ago when a body was removed from the Tomb of the Unknown Soldier in Washington D.C. and the identity of that soldier was determined.

In most cases, DNA testing has been beneficial. However, for those who wish to hide their identity (such as fathers who do not want to take financial responsibility for their children), it has unwanted consequences. For families researching their background, it is much more reliable and less time-consuming than constructing the **genealogy** of a person. However, it can also reveal things that they do not want to know, forever changing a person's concept of family and self. Furthermore, DNA testing has become a business. Even funeral homes and burial services now offer to save DNA samples (e.g., hair, blood) for a fee. This raises questions of both privacy and ethics. What are the rights of the dead person? Who has access to these samples? How and where should they be stored? What happens to the samples if the storage company goes bankrupt?

Genetic Testing for Diseases: Advantages and Disadvantages

Genetic testing for diseases is also a significant part of our lives now. The sequencing of the **human genome** has made it possible to identify and link genes to diseases such as Tay-Sachs, diabetes, breast cancer, and even **obesity**. As these genes are identified, tests are also developed to **detect** their presence in human **tissue samples**. This technology is being put to use in several ways. It allows parents to identify the genetic features of a baby before it is born, young adults to determine whether they have inherited the genes for a particular disease, and scientists to create computer data banks that contain information from genetic testing.

Below is a list of diseases that may be caused by damaged genes and an explanation of these diseases.

Disease	**Effects**	**End Results**
Tay-Sachs	damage to the nervous system	affects children; incurable
Alzheimer's	loss of memory	affects older people; incurable
diabetes	imbalance in an individual's blood sugar. If it is not controlled, it can damage an individual's eyes, kidney's and other organs.	one type begins in childhood; a second type begins in adulthood; controllable with medication
Huntington's	a degenerative brain disorder. It slowly diminishes an individual's ability to walk, think, talk	affects people aged thirty to forty; incurable

	and reason.	
Lou Gehrig's or ALS	affects and eventually destroys an individual's voluntary muscle action. Patients in the later stages of the disease become totally paralyzed.	Affects middle aged adults; incurable
Multiple sclerosis	slowly destroys the central nervous system	affects people in their 20s and 30s; often results in **paralysis** and death, although not everyone with the disease dies.
Sickle Cell Anemia	malformed red blood **cells** cause pain, damage, low blood count, and anemia. It can damage major organs such as kidneys and eyes.	**afflicts** certain ethnic groups; may lead to death
Breast cancer	malignant cells in the breast	affects women; can be controlled with surgery and drugs, but may lead to death
Colon cancer	malignant cells found in the colon or rectum	affects men and women; can cause death
Ovarian cancer	malignant cells found in women's reproductive organs	affects women; usually leads to death

Although this area of research appears to be similar to **DNA testing**, it has more **potential** disadvantages. While **genetic testing** allows parents to determine if their unborn baby will suffer from any life-threatening illnesses or profound mental defects, it also brings with it the possibility that parents might try to create "designer babies." Genetic testing gives adults access to information about **inherited diseases** that can be successfully controlled or treated through changes in lifestyle or medication. However, if the disease is incurable and **devastating** (for example, Alzheimer's, Huntington's, Lou Gehrig's disease), living with this knowledge may be more of a curse than a blessing. It may affect people's decisions about whether to have children or to get married. In short, it may change their lives completely. In extreme cases, it may even lead them to consider or attempt suicide.

We may have too much faith in genetic testing. Because of these tests, we tend to believe that our genetic inheritance is our **destiny**. However, the tests themselves are problematic in several ways. First, they are not always 100 percent accurate. The technology is still relatively new and the results of genetic tests, like any other medical tests, can be misinterpreted. Second, even if a test shows that an individual carries the gene for a disease, this does not necessarily mean that he or she will get the disease. Other factors such as lifestyle, diet, and even the environment may have more effect upon a person’s health than the presence of the gene. Thus, while information from genetic testing may provide important clues about our health, it should not change the way that we define ourselves.

In addition to these practical and ethical concerns about genetic testing, this technology may threaten a person’s right to privacy. Since the information from genetic testing is stored in a computer, it can be accessed—both by those who have legal right to see it (for example, a doctor) and those who do not (an employer). An important concern here is that insurance companies, employers, and the media might find information and use it against an individual, for example, to deny them insurance coverage or to fire them from a job. Similarly, in an election campaign, the media might reveal medical information about a candidate that would seriously hurt his or her chances of being elected.

Benefits and Dangers of Gene Therapy

In addition to genetic testing, which **detects** diseases, scientists are beginning to develop therapies to treat diseases that have a genetic origin. This therapy works in two ways. In the first, **gene transfer**, researchers replace “bad” DNA with “good” DNA. In the second, gene repair, researchers block or stop the action of a harmful gene. These therapies are still highly experimental, and there have been numerous **side effects** during testing such as fevers, abnormal **blood clotting**, partial **paralysis**, and even death. One extreme instance of such problems happened with Jessie Gelsinger, who died after receiving genetic therapy at the University of Pennsylvania in the U.S.. Doctors inserted a cold virus into Gelsinger’s liver in order to cure his genetic disease. Instead, the therapy caused his **immune system** to attack and destroy not only the harmful virus but also his heart, **liver** , and kidneys. This case is especially regrettable because scientists encouraged the patient to **undergo** this therapy, but did not tell him about the **potential** dangers.

In addition to the physical dangers of gene therapy, there are also ethical issues. At what stage in a person’s illness will gene therapy be used—as soon as the illness is discovered or only after all other traditional methods have failed? Who will be responsible for **conducting** gene therapy—university researchers, medical doctors, or **pharmaceutical companies**? Who will have access to this expensive technology—people in rich, developed countries or people in poorer, developing areas of the world? These and other questions will continue to concern society as DNA and gene technology advance.

CLASSROOM APPLICATIONS

One of the fastest-growing areas of medical research is that of genetic testing and gene therapy. This chapter introduces students to this area of DNA research and helps them explore the related ethical issues.

PRELIMINARY LESSON PLANNING

Materials:

Prepare enough copies of the student handouts in **Appendix B**, **Appendix C**, and **Appendix E** for each student in the class.

For the Cool Down Activity, bring enough pens and overhead transparencies (or sheets of paper large enough to be displayed on the blackboard) for each group in the class.

Student Grouping:

Decide on procedures for grouping students for each activity (see suggestions below). Groups should have no more than six participants.

For most activities, you should group students heterogeneously—either by language proficiency level or, for those activities where language is less of an issue, by expertise (that is, how much group members know about the topic). For some activities, you may wish to group randomly. In class contexts where students have varied first languages, it is important to put students from different backgrounds into each group.

Vocabulary:

Before teaching the lesson, preview the glossary items and select those items that need to be pre-taught (that is, those that are absolutely essential for introducing and understanding the topic). These will probably include key concept words such as DNA testing, genetic testing, gene therapy and words for genetically-linked diseases such as Alzheimer's, Huntington's, Lou Gehrig's disease, Tay Sachs, breast cancer, ovarian cancer, and sickle cell anemia.

WARM UP ACTIVITY (APPROXIMATELY 5–10 MINUTES)

Purpose:

- To preview key issues in genetic research and therapy
- To encourage students to examine what they believe about these issues

To activate vocabulary related to the topic

Procedures:

- Give each student a copy of Handout 1 (**Appendix B**). Ask them to read the statements in Column 1 and circle YES, NO, or MAYBE.
- Have students find a partner and discuss their responses.
- Tally responses as a whole class.
- Choose the two statements that received the most YES and the most NO responses. Have students give reasons for their responses.

Transition from Warm Up to Activities

Tell students that the class session will be spent discussing controversial issues surrounding the new technologies of DNA identification and gene therapy.

ACTIVITY 1 (APPROXIMATELY 30–40 MINUTES)

Purpose:

- To introduce students to cases in which genetic science has been used to solve human problems
- To introduce content-specific vocabulary and concepts
- To provide a forum for students to examine their beliefs about the value of genetic research
- To activate student speaking and listening skills

Procedures:

Write these purposes for genetic tests and therapy on the blackboard:
—to prove a person guilty or innocent of a crime
—to recreate an extinct species
—to determine identity and ancestry

—to cure a life-threatening disease
—to detect the presence of a disease-causing gene

Divide the class into groups of from two to five students. The total number of groups will depend on the number of students in the class.

Distribute a copy of Handout 2, **Appendix C** to each student and have them do the following:
a. Read each of the cases in the handout.
b. Work with other group members to determine the purpose of genetic testing or therapy. Note that one purpose may fit more than one case.

Tell the students that they represent an agency that distributes funding for biological research and development. They should look at their pairing of purposes and cases of genetic testing and therapy, and decide which purpose is the most worthy of funding. Tell them to be prepared to defend their choice.

Have students present their choices.

ACTIVITY 2 (APPROXIMATELY 30 MINUTES)

Purpose:

To provide students with a real-life application of the decision-making process involved in genetic testing

To give students an opportunity to participate in this decision-making process

Procedures:

Pre-teach the following vocabulary: sickle cell anemia, genetic testing, carrier, afflict

Read aloud the case history of the Allen family in **Appendix D.**

Have students take notes as you read the case.

Have students in pairs compare their notes in order to reconstruct the case history.

As a whole class, review the facts of the case and generate a list of dilemmas that this family has faced. Write these dilemmas on the blackboard (see list of sample dilemmas in **Appendix D**).

Divide the class into groups of from two to five students. The total number of groups will depend on the number of students in the class. Have them select one of the dilemmas on the blackboard and discuss whether they agree or disagree with the Allens' decision (see sample phrases for expressing an opinion in **Appendix D**).

Have groups report back their discussion to the whole class.

ACTIVITY 3 (APPROXIMATELY 20 MINUTES)

Purpose:

- To provide a forum for students to discuss the role of genes and the environment in diseases known to be genetically linked
- To give students an opportunity to discuss lifestyle choices they have made in order to improve their health

Procedures:

1. Explain to students that genes don't always determine health and that other factors (such as lifestyle and a family's history of disease) can be equally important in determining whether or not a person contracts a disease.

2. Divide the class into groups of from two to five students. The total number of groups will depend on the number of students in the class.

3. Distribute a copy of Handout 3, **Appendix E** to each student. Tell students to do the following:
   a. Study the table.
   b. Using the information from the table, work with other group members to answer the following question: "Do genetic tests reliably predict a person's chances of getting a genetically-linked disease?" Be prepared to defend your answer.

4. Ask each group to state its opinion and give one reason why they hold this opinion (see sample phrases for expressing an opinion in **Appendix D**).

5. As groups present, write their reasons on the blackboard.

COOL DOWN ACTIVITY (APPROXIMATELY 30 MINUTES)

Purpose:

- To wrap up the lesson
- To review important concepts and vocabulary
- To provide focused speaking and listening opportunities

Procedures:

1. Write the following three concepts on the blackboard: genetic testing, DNA testing, and gene therapy. Ask the class to explain the differences between these concepts.

2. Divide the class into three groups. The total number of members in each group will depend on the number of students in the class. Groups should contain no more than five students each. Assign each group a letter designation A, B, or C. With a large class, you can create more than one group for each letter.

3. Distribute an overhead transparency (or large sheet of paper) and a pen to each group.

4. Have each group choose a secretary.

5. Assign topics to each group (A = genetic testing, B = DNA testing, C = gene therapy).

6. On the transparency or large sheet of paper, have them list the pros and cons of this application of genetic research.

7. Have students display their lists and explain their rationale.

POSSIBLE EXTENSIONS TO LESSON

1. For the Warm Up Activity, have students select one of the statements in **Appendix B** and write a journal entry explaining their position.
2. For homework related to Activity 1, encourage students to think of one or two cases they are familiar with that are similar to those listed in the activity. Have them report these at the beginning of the next class session or have them write about one case history as homework.

3. For Activity 3, as an in-class or out-of-class activity, have students make a list of the factors they can and can't control in their own lifestyle.
4. Have students visit one of the Web sites listed in this chapter or locate an article on gene research in a newspaper or magazine, and find one interesting piece of new information to explain to the class.

Refer to the websites listed in the next section of this chapter for more information and lesson planning ideas.

INTERNET APPLICATIONS

(Websites with prepared lesson plans and activities)

Genetic Learning Center
http://gslc.genetics.utah.edu/
This site includes on-line, hands-on, and group activities, as well as links to thematic activities on basic genetics and genetic disorders.

DNA: The Instruction Manual for All Life
http://www.thetech.org/genetics/
This is a fun interactive teaching guide by the Tech Museum of Innovation about DNA and how it affects you.

Think Quest: Genetics
http://library.thinkquest.org/03oct/00737/
This site provides a description of and links to several excellent lessons on genetics and related issues, both at the basic and advanced levels, some with ready-made quizzes

Exploitable Content
(Web sites with information about the topic, but without any prepared lessons.)

1. **Your Genes, Your Choices: Exploring the Issues Raised by Genetic Research**
   http://www.ornl.gov/sci/techresources/Human_Genome/publicat/genechoice/index.html
   This free book describes the Human Genome Project, the science behind it, and the ethical, legal, and social issues that are raised by the project. This book was written as part of the Science + Literacy for Health project of the American Association for the Advancement of Science (AAAS) and funded by the U.S. Department of Energy.

2. **Ethical, Legal, and Social Implications (ELSI) of Human Genetics Research**
   http://www.genome.gov/page.cfm?pageID=10001618
   The ELSI Program was established in 1990 to address the ethical, legal and social issues of human genetic research. This site provides information on the history of ELSI and research and training opportunities at the National Human Genome Research Institute (NHGRI).

3. **The Human Genome Project**
   http://www.genome.gov/page.cfm?pageID=10001694
   Also by the NHGRI, this site provides detailed information on how the Human Genome Project was initiated, its progress, who is involved, opportunities for research funding, and HGP-related publications and information sources.

4. **To Know Ourselves**
   http://www.ornl.gov/hgmis/publicat/tko/index.html
   This site by the Human Genome Project provides a review of the role, history, and achievements of the Department of Energy in the Human Genome Project and an introduction to the scientific and other aspects of the project.

5. **Mad Sci Network**
   http://www.madsci.org/
   This is an excellent site for finding answers to questions. A staff of science experts is available to answer nearly any question you may have. Simply enter a "key term" for a question you have and you will see what answers

have already been provided. This link (**http://www.madsci.org/info/class.html**) gives instructions for how this site can be used most effectively in the classroom. It also provides links to lessons.

6. **About Biotech**
   http://www.accessexcellence.org/AB/
   This site by the National Health Museum provides information about current biotechnology projects and their likely impact on life in the 21st century. Also, the Graphics Gallery **http://www.accessexcellence.org/AB/GG/** contains material for classroom use.

7. **DNA Chip – Genetic Testing of the Future**
   http://www.ndsu.nodak.edu/instruct/mcclean/plsc431/students99/althoff.htm
   This is informative reading for advanced level students.

Official Documents

The National Human Genome Research Institute (NHGRI)
http://www.genome.gov/
This organization funds research in chromosome mapping, DNA sequencing, database development, technology development for genome research, and studies of the ethical, legal, and social implications of genetics research.

REFERENCES

Alter, J. (2000, June 12). *The death penalty on trial*. Newsweek, pp. 24–34.

Begley, S. (2000, April 10). *Decoding the human body*. Newsweek, pp. 50–57.

Couzin, J. (1999, November 1). *Quandaries in the genes*. U.S. News and World Report, pp. 64–66.

Cowley, G., and Underwood, A. (2000, April 10). *A revolution in medicine*. Newsweek, pp. 51–67.

Fischer, J. S. (2000, February 14). *Best hope or broken promise?* U.S. News and World Report, p. 46.

Jacobs, P., and Zitner, A. (2000, June 27). *Scientists reach milestone in mapping of human genome*. Los Angeles Times, A1, pp. 12–13.

McGraw, D. (2000, June 12). *DNA and the death penalty*. U.S. News and World Report, pp. 20–21.

Marcus, M. B. (2000, May 8). *DNA from the dead may offer little to the living*. U.S. News and World Report, p. 65.

Park, A. (2000, October 16). *Designer baby*. Time, p. 102.

Roberts, L. (1999. December 20). *It's alive! (or might be)*. U.S. News and World Report, p. 61.

Shute, N. (2000, July 24-31). *Haven't got a clue? Maybe DNA will do*. U.S. News and World Report, pp. 78–79.

Sobel, R. K. (2000, February 21). *Add insult to injury: Gene therapy's travails*. U.S. News and World Report, p. 55.

APPENDICES

APPENDIX A

Glossary

Afflict: Cause pain or suffering.

Ancestry: The descendants or blood relative of one individual.

Blood clotting: A process in which liquid blood changes into a semisolid (a blood clot).

Carrier: An individual who does not show symptoms of a disease but has the genes for it and can transfer it to his/her child.

Cell (human): In biology, a structure surrounded by a membrane and containing genetic material (DNA) on the inside. Considered by most biologists to be the basic unit of life.

Chromosome: In organisms without a nucleus (such as bacteria), this is a circular DNA molecule used in genetic engineering. In organisms with a nucleus (including plants and humans), this is one of the threadlike structures within the nucleus that contains DNA.

Conduct: To act, guide, or manage (usually conduct research or experiments).

Convict: To find or prove (someone) guilty of an offense or crime, especially through the verdict of a court.

Destiny: Fate. A future that an individual cannot control.

Detect: To notice; to find; often used to describe the discovery of a disease.

Devastating: Terrible; causing great harm.

DNA: (deoxyribonucleic acid) A molecule in the form of a double helix , found within a structure known as a chromosome, within the nucleus of every living cell. First discovered in the 19th century, it controls the daily operation of a cell, and provides the genetic "blueprint" for the physical characteristics of all living organisms.

DNA testing: The analysis of human DNA, RNA, chromosomes, and proteins in order to detect the presence or potential presence of an inheritable disease.

Ethics: A set of principles of proper conduct. A system of moral values.

Extinct: No longer existing or living.

Gene: A small stretch of DNA that directs the production of proteins. A hereditary unit that occupies a specific position (locus) on the chromosome. This unit has a specific effect on the physical characteristics of the organism and can house one of many different allele forms (each allele causes a different trait).

Genealogy: A record or chart of a person’s extended family going back many generations; a family tree.

Genetic make-up: All the chromosomes and the information they contain. The genes of an individual.

Genetic testing: The checking of an individual's genetic material to predict present or future disability or disease, either in the individual or his/her children.

Gene therapy (human): Insertion of normal DNA directly into cells to correct a genetic defect.

Gene transfer: The movement of genetic material (DNA) from the laboratory into a human subject.

Human genome: The full collection of genes in a human being.

Immune system: A system which protects the body from disease causing agents.

Inherited disease: A disease or disorder that is inherited genetically.

Liver: An organ in the body which helps with metabolism, digestion, detoxification, and elimination of substances from the body.

Malignant cells: Cells that grow uncontrollably.

Obesity: The condition of having excessive body fat.

Paralysis: The loss of motor functions; the inability to move one´s muscles.

Pharmaceutical companies: Companies that make drugs or medicines.

Potential: 1. Possible. 2. Able to grow and develop.

Side effect: An unexpected, usually undesirable reaction to a medicine or therapy.

Tissue sample (human): A small portion of a group of similar cells taken for research of medical purposes.

Trial: The formal presentation of evidence and arguments when a person is accused of a crime.

Undergo: To experience; to endure; to suffer.

APPENDIX B

(**Printer-Friendly Format**)

Handout 1 for Warm Up Activity

1) I would have a genetic test to determine if I had the gene for an incurable disease.	YES	NO	MAYBE
2) I would allow a potential employer to administer a genetic test before hiring me.	YES	NO	MAYBE
3) I would ask my relatives to save samples of my DNA after my death.	YES	NO	MAYBE
4) If I were accused of a crime, I would undergo a DNA test to prove my innocence.	YES	NO	MAYBE
5) I would pay a company to protect the privacy of my genetic information.	YES	NO	MAYBE
6) I would undergo gene therapy to cure a devastating or life threatening disease.	YES	NO	MAYBE

7) I would save the DNA of my dead loved ones.	YES	NO	MAYBE
8) I would use gene therapy to insure the sex or improve the genetic make-up of my unborn baby.	YES	NO	MAYBE

APPENDIX C

(**Printer-Friendly Format**)

Handout 2 for Activity 1

1) Four black men were convicted of the 1978 murders of a white couple in Chicago, Illinois in the U.S. Two of the men were on death row waiting to be executed when DNA evidence showed that they could not have been the ones who raped the woman victim. As a result, they were released from prison. Later, three other men confessed to the crime and were convicted.
2) After the execution of the last Russian Czar Nicholas and his family during the Russian Revolution, the bodies of the two youngest children, Alexis and Anastasia, were never found. Until her death in 1984, Anna Anderson claimed to be the long-lost Crown Princess Anastasia. In tests, her DNA was compared to that of Prince Philip of Great Britain, a descendant of the Russian royal family. There was no match. Her identity as Franzisca Schonzkowska was established when her DNA was compared with that of a Polish nephew.
3) Nancy Seeger, a 56-year-old woman from Illinois in the U.S., worried her whole life about developing breast cancer since both her mother and her aunt had died from this disease. She was tested and found to have an 85% risk of breast cancer and a 50 percent risk of ovarian cancer. As a result of this information, she decided to have surgery.
4) A woman from California in the U.S., Ginger Empey, had advancing breast cancer. Since it had already spread to major organs when diagnosed, gene therapy was the only choice. She was injected with a genetically-engineered drug. Over the next year, her tumors shrank by 25 percent. After 3 years, they almost disappeared.
5) Ms. X, had given her daughter up for adoption many years before and had agreed to conceal her identity. However, she was not happy with her decision. Later in life, she searched and found a young woman whom she believed to be her daughter. The young woman was not sure that Ms. X was her mother, especially because the woman who claimed to be her biological mother was Jewish and she was raised as a Christian. DNA testing was used to prove the parental link.
6) O. J. Simpson, a well-known U.S. sports figure, was arrested on June 17, 1994 as a suspect in the double murder of his ex-wife Nicole and her friend Ronald Goldman. In the trial, DNA testing showed that blood found at the crime scene belonged to Simpson. This evidence was later successfully challenged by Simpson's lawyers. He was found not guilty.
7) Scientists recently discovered the completely frozen carcass of a wooly mammoth, an ice age animal that has been extinct for thousands of years. They are hoping to extract DNA from the frozen animal and use it to recreate this species.

Case Study for Activity 2

Michelle Nicole Allen was born in 1978. A few months after her birth, it was determined that she suffered from sickle cell anemia, a blood disease common in people of African American descent. In 1983, Michelle's mother became pregnant again and gave birth to a son, Michael, who developed the disease seven months later. Both children spent much of their childhood in hospitals. Michelle has now reached adulthood despite this grave illness. Michael is in his teens and, despite being hospitalized more often than his older sister, leads an active life that includes playing four musical instruments. Their mother is glad there was no genetic test available for sickle cell anemia when she was pregnant.

Michelle, at age 21, became pregnant and gave birth to a son, Philip. Before his birth, she was given the option of having genetic tests to determine if her son was a carrier for sickle cell. She opted against this test. Since Philip was born, he has been tested four times. Three times he tested positive and once negative. The family must now wait to see if Philip will develop the disease. It is their hope that the third generation of their family will not suffer from this illness.

Sample Dilemmas for Activity 2

Michelle's mother's dilemmas:

- Whether or not to have a second child who might also have sickle cell anemia
- Whether she should protect her children's health or allow them to lead an active, normal life

Michelle's dilemmas:

- Whether or not to get pregnant at all
- Whether to have a genetic test to determine if her unborn child is a carrier of sickle cell anemia
- What to do if Philip develops the disease

Michael's dilemmas:

- Whether or not to get married
- Whether or not to have children
- If his wife becomes pregnant, whether or not to allow genetic testing for the unborn child

Sample Phrases for Activity 2: Expressing an Opinion

Expressing an Opinion	**Disagreeing**	**Agreeing**
In my opinion…	I can see your point but…	That's a good point because…

I'd like to say that…	I'm not sure I agree. I think…	That's my feeling, too.
I think that…	But don't you think that…	I couldn't agree more.
As I see it…	Are you saying that…?	I tend to agree with that.

APPENDIX E

Handout 3 for Activity 3

Disease	Relationship of genes to disease	Risk of getting disease	Other factors contributing to disease risk
Breast cancer	Scientists have found one specific gene in many breast cancer sufferers.	50–85%	• Lifestyle (diet, exercise, level of stress) • Environment in which you live • Incidence of the disease in immediate family • Other genes associated with this disease
Ovarian cancer	Scientists have found one specific gene in many ovarian cancer sufferers.	20–40%	• Lifestyle (diet, exercise, level of stress) • Environment in which you live • Incidence of the disease in immediate family • Other genes associated with this disease
Huntington's	Scientists have found the same gene in all sufferers. They call it the "Huntington's gene."	nearly 100%	• No other known factors

Colon cancer	Scientists have found one gene that has a connection to colon cancer.	100%	• No other known factors except in a very small number of colon cancer cases
Alzheimer’s	Scientists have found one gene that has a connection to Alzheimer’s disease.	unknown	• Other possibly-related genes are also being researched