MODULE 7

Solving and sharing the mysteries of genes

FACILITATOR'S GUIDE

GENETICS FOR KIDS

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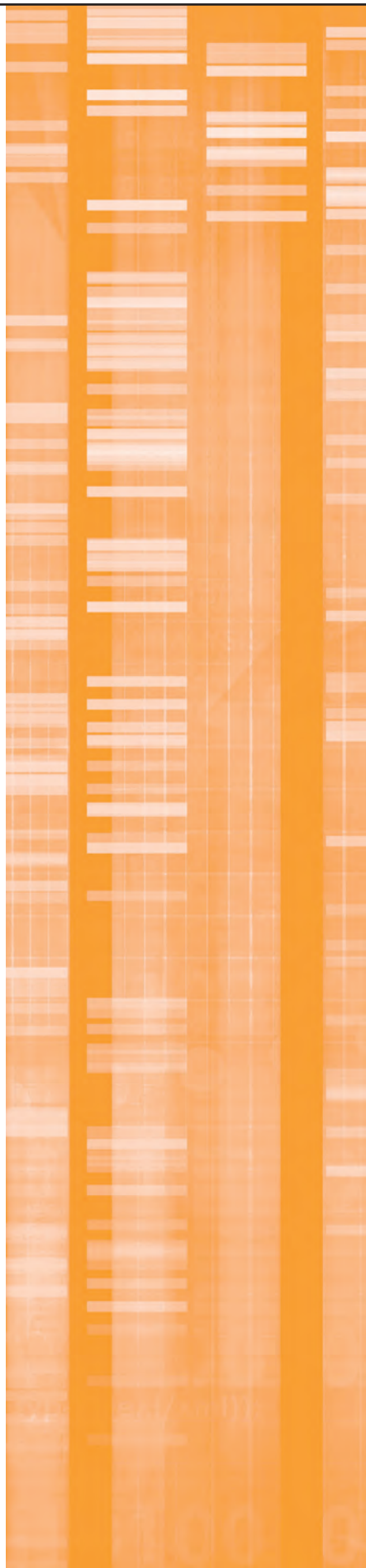
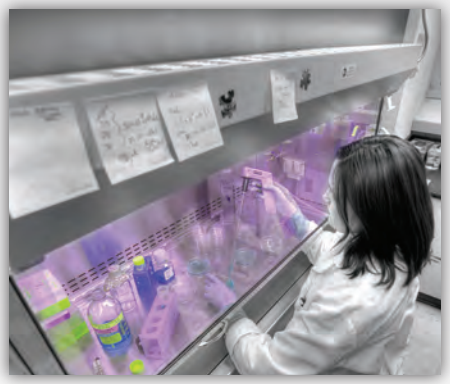


Solving and sharing the mysteries of genes

Introduction



Scientists use DNA testing to examine a person's DNA and identify genetic markers. A genetic marker is a section of DNA that indicates a greater chance that a person will get a disease. Having a genetic marker does not necessarily mean that a person will get a disease. Many genetic markers seem only to indicate an increased chance or probability of a person getting a disease.

As costs for DNA testing decline, many researchers advocate testing everyone's DNA for potential health problems. Although identifying genetic markers through DNA testing has great potential for the common good, many people are concerned about the privacy of their genetic information. People are concerned that if a genetic marker were discovered in their DNA, the information may be sold, stolen, or released to employers and insurance agencies. This may potentially cause a person to lose her job and/or her insurance coverage, since employers and insurance agents do not want to risk the high cost of a person getting a genetic disease.

In this module, students will read and discuss three scenarios about DNA testing for genetic markers. Students will learn about DNA testing for a genetic marker for breast cancer, DNA testing *in vitro* embryos before implantation into the prospective mother's uterus, and DNA testing for genetic diseases. The main objective of the module is for students to understand and evaluate the possible benefits and risks of DNA testing for genetic markers. Students will work in groups to read background information and then answer a set of questions for each scenario. The module involves topics that may be sensitive to some students. Consideration may be given to how to best discuss these topics with your class.

Prior to implementing the module, consider how comfortable you are discussing the three scenarios. Students will pick up on your level of comfort and reflect it in their handling of the topics. One way to increase your comfort level is to become knowledgeable about these complex issues. The additional resources listed at the end of the module may be helpful in increasing your knowledge about the topics discussed in the scenarios.

Learning Objectives

- ✓ Know what genetic markers are and how they are used in medical and scientific fields
- ✓ Recognize that genetic markers cannot perfectly predict who will get a disease
- ✓ Understand the potential personal and societal implications of DNA testing

Prior Knowledge

To complete this module, students should already be able to:

- ✓ Recognize that chromosomes are made of DNA
- ✓ Explain how chromosomes are inherited
- ✓ Understand that genes are sections of chromosomes that give directions for traits
- ✓ Explain how variation in genes produce variation in particular traits

Relevant Standards of Learning

National Science Education Standards
Life Science, Content Standard C

Structure and function in living systems

- All organisms are composed of cells–the fundamental unit of life. Most organisms are single cells; other organisms, including humans, are multicellular.

Reproduction and heredity

- Every organism requires a set of instructions for specifying its traits. Heredity is the passage of these instructions from one generation to another.
- Hereditary information is contained in genes that are located in the chromosomes of each cell. Each gene carries a single unit of information. An inherited trait of an individual can be determined by one gene, or by many genes. A single gene can influence more than one trait. A human cell contains many thousands of different genes.

New York State Intermediate Science Standards (Grades 5 - 8)
Standard 4: The Living Environment

Major Understandings

- 2.1a: Hereditary information is contained in genes. Genes are composed of DNA that makes up the chromosomes of cells.
- 2.1e: In sexual reproduction typically half of the genes come from each parent. Sexually-produced offspring are not identical to either parent.

Background

Scientists use **DNA testing** to examine a person's DNA and determine the likelihood that a person will get a disease by identifying particular genetic markers for a disease. A **genetic marker** is a section of DNA that indicates a greater likelihood that a person will get a disease *(see Teacher Note 1)*. Having a genetic marker for a disease does not necessarily mean that a person definitely has or will get the genetic disease. Other factors, such as a person's environment, overall health, and nutrition may moderate the risk of getting a disease.

There is much research into what genetic markers may tell about a person's genetic predispositions. It is important to note that not all people with a genetic marker for a disease will actually get the disease or behave a certain way. Many genetic markers seem only to indicate that there is an increased probability of a person getting a disease or behaving in a certain way.

Knowledge of genetic markers may be associated with ethical dilemmas *(see examples below)*. An example of genetic markers for a disease is the BRCA1 and BRCA2 genetic markers for breast cancer. BRCA1 and BRCA2 are tumor suppressor **genes**. BRCA1 and BRCA2 help repair DNA if the DNA gets damaged, which may prevent cancer from forming. Some women have mutations, or changes, to BRCA1 and BRCA2. Without normal BRCA1 and BRCA2 genes, a body may not be able to repair damaged DNA, and damaged DNA leads to the formation of breast cancer. In short, if women have the BRCA1 or BRCA2 genetic marker for breast cancer, they are more likely to develop breast cancer. If women know that they have the BRCA1 or BRCA2 genetic markers, they may take preventative steps to reduce their risk of breast cancer. Preventative steps vary dramatically from yearly mammograms or magnetic resonance imaging (MRIs), to anticancer drugs, to full bilateral mastectomies.

Ethical dilemmas related to genetic markers may also arise when couples, who have difficulty conceiving a baby, turn to *in vitro* fertilization (IVF). IVF is when an embryo is developed in a laboratory from the reproductive cells of the couple or a donor. Prior to implantation, many embryos are screened for genetic markers that indicate likely risks of certain diseases. Based on the results of the test, couples have the choice of whether or not to implant the embryo in the uterus of the prospective mother.

The potential for misuse of information about DNA exists. Some companies have used DNA testing to determine whether their employees have genetic markers for certain diseases. In 2001, for example, the Burlington Northern Santa Fe Railway (BNSFR) was accused of testing the DNA of 36 employees for genetic markers of carpal tunnel syndrome without their consent. BNSFR eventually settled a lawsuit with a payment of $2.2 million to the affected employees.

In 2008, to combat the use of DNA testing for discriminatory practices, the United States passed the Genetic Information Nondiscrimination Act of 2008 (GINA), a law that states that Americans cannot be discriminated against by health insurers and employers because of differences in their DNA that may affect their health *(see Teacher Note 1).*

Vocabulary

1. **Deoxyribonucleic acid (DNA)**: A hereditary material that contains instructions for making proteins used in the body.
2. **DNA testing**: Examining a person's DNA to analyze their traits and to look for genetic markers related to certain diseases and behaviors.
3. **Genetic disease**: A disease that is caused by abnormalities in genes or chromosomes.
4. **Genetic marker**: A section of DNA that indicates a greater chance that a person will get a disease. Having a genetic marker does not necessarily mean that a person will get a disease. The marker may be a segment of DNA with no known function.
5. **Health insurance**: Pays for all or parts of a person's health care bills.
6. **Mutation**: A change in the sequence of an organism's DNA.

Materials List

Before you begin, ensure that you have all of the items necessary to complete the module.

- ✓ Student Handout
- ✓ Large piece of chart paper or whiteboard
- ✓ Markers

Procedure

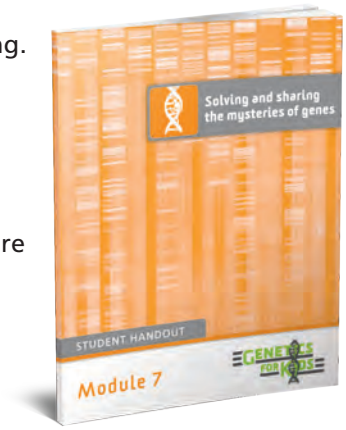
Because of the sensitive topics being discussed, it might be an advantage to have single-gender groupings. Some students may be sensitive to the three scenarios in this module. The scenarios include DNA testing for a genetic marker for breast cancer, DNA testing for genetic diseases, and DNA testing *in vitro* embryos before implantation into the uterus of the prospective mother.

All of these scenarios may have echoes in students' families. Strong views must be moderated with attention to the words you use. Remember to remain impartial. Focus on helping the students base their arguments and discussions on scientific evidence and logic. A judgmental position may easily be interpreted as a negative judgment about a family member or family situation.

Take into account the values and beliefs held by the population of students and their families. Although adolescents are able and ready to begin dealing with moral complexities involved in bioethical decisions, families may feel strongly about discussing these moral complexities in an environment that excludes family values and beliefs.

You should also consider and anticipate student reactions and questions prior to implementing the module. As you circulate around the room listening to group discussions, be attentive to behaviors that may indicate that a group needs your guidance or reassurance.

Despite the challenging nature of the module, the topics are important for students' understanding of the ethical and personal implications of DNA testing.



Day of the Lesson

1. Seat students in groups of four.

   Inform students that in today's module, they will be learning about genetic markers in DNA that indicate risk of certain diseases. Explain that students are to read and discuss three different genetic marker scenarios in small groups.

2. Distribute a **Student Handout** to each student.

3. Instruct students to read **Part I: Introduction**.

   Ask students to silently read **Part I: Introduction** on the **Student Handout**. Provide students with enough time to read the introduction. Circulate around the room as students read. Redirect students with questions, and check for comprehension as needed.

4. Emphasize key points from **Part I: Introduction**.

   When all students are finished reading, address any questions students may have about genetic markers. Emphasize the following key points:

   - A genetic marker for a disease is a section of DNA that indicates a likelihood that a person will get a disease. Genetic markers indicate a person has a greater risk of getting a disease. Genetic markers do not guarantee a person will get a disease.
   - A child inherits her genes from her mother and father. A child has no control over which genes she receives, and the parents have no control over which genes combine to create the child.
   - Loss of privacy may be a risk of DNA testing for genetic markers. There is always the risk that the results of a genetic test may be stolen, sold, or released to people who will use the information in an unethical or illegal manner.

5. Check students' understanding of **Part I: Introduction**.

   After you have emphasized the key points of the introduction, ask students the following questions:

   - Would they want to get their own DNA tested? Why or why not?
   - Should employers, insurance companies, and schools be allowed to require that people get their DNA tested for disease markers?

6. Instruct students to complete **Part III: Activities** with their small groups.

   Inform students that in ***Activity 1: What would you do?*** they will discuss three different scenarios about DNA testing and genetic markers. They will read about a genetic marker for breast cancer, DNA testing *in vitro* embryos before implantation into the uterus of the prospective mother, and DNA testing for genetic diseases. Students do not need to work through the scenarios in order. If time is a concern, students may complete two of the three scenarios before reconvening as a class. Alternatively, you may assign different scenarios to different groups.

   Instruct students to read the scenarios aloud to each other, with each person taking a turn reading aloud.

   Inform students that they will discuss the readings in their groups, and may work together to answer the questions following each reading, and write down key points from the answers of each person in the group.

Inform students that there are no right or wrong answers to the questions, and that each scenario has pros and cons. Students may disagree, but need to be respectful of each others' opinions. If a student chooses to not speak on an issue, then he or she may record the group's responses.

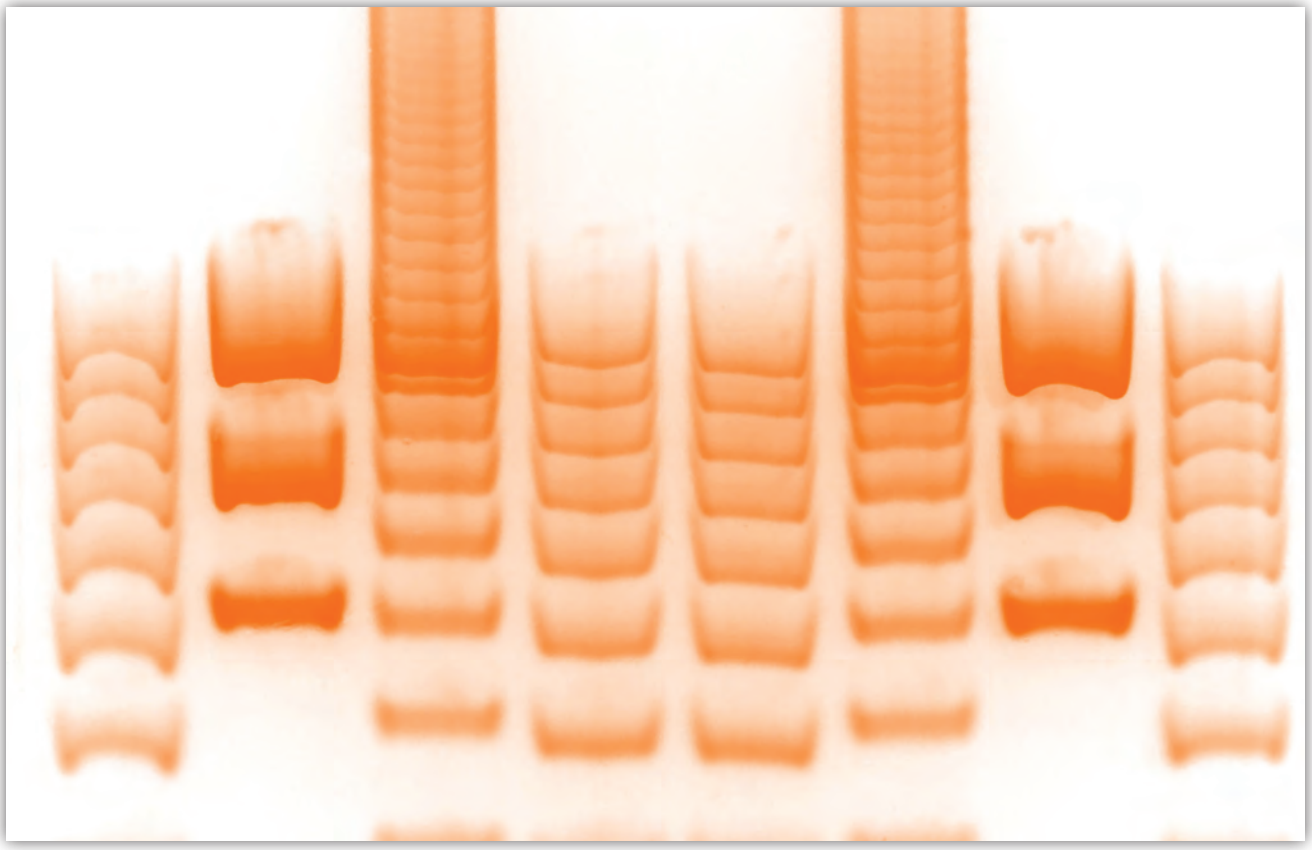
7. Circulate around the room and answer questions as students work through **Part III: Activities**.

   Circulate around the room as students work to ensure all students write down individual responses. Make sure students are speaking respectfully about the scenarios and that they are on task.

8. Lead a closing class discussion about the module's activities.

   Take a quick poll to find out which scenarios students completed in their groups. Start with the scenario most groups chose first and ask each group to share their responses. Record student answers in an Agree/Disagree T-chart written on the board or on a large piece of chart paper. Students may agree or disagree that genetic testing is beneficial for each of the three scenarios. Urge students to consider the pros and cons for each scenario.

	Agree *(Genetic testing)*	**Disagree** *(No genetic testing)*
Breast cancer		
Embryo screening		
Test your DNA		



Example of DNA separation.

Extension Lesson

Genetic Inheritance Inverviews

Students may investigate the diagnoses and treatments of diseases discovered through genetic markers. Students may interview someone who is managing a genetic disease, or someone who is a caregiver for people with inherited conditions. Consider inviting a speaker into the classroom. A genetic counselor may be able to discuss the implications of testing for inherited disorders. A researcher may specialize in genetic disorders, and may be able to discuss genetic diseases such as Huntington's disease, a genetic disease in which where the genetic marker guarantees emergence of the disease.

Additional Resources

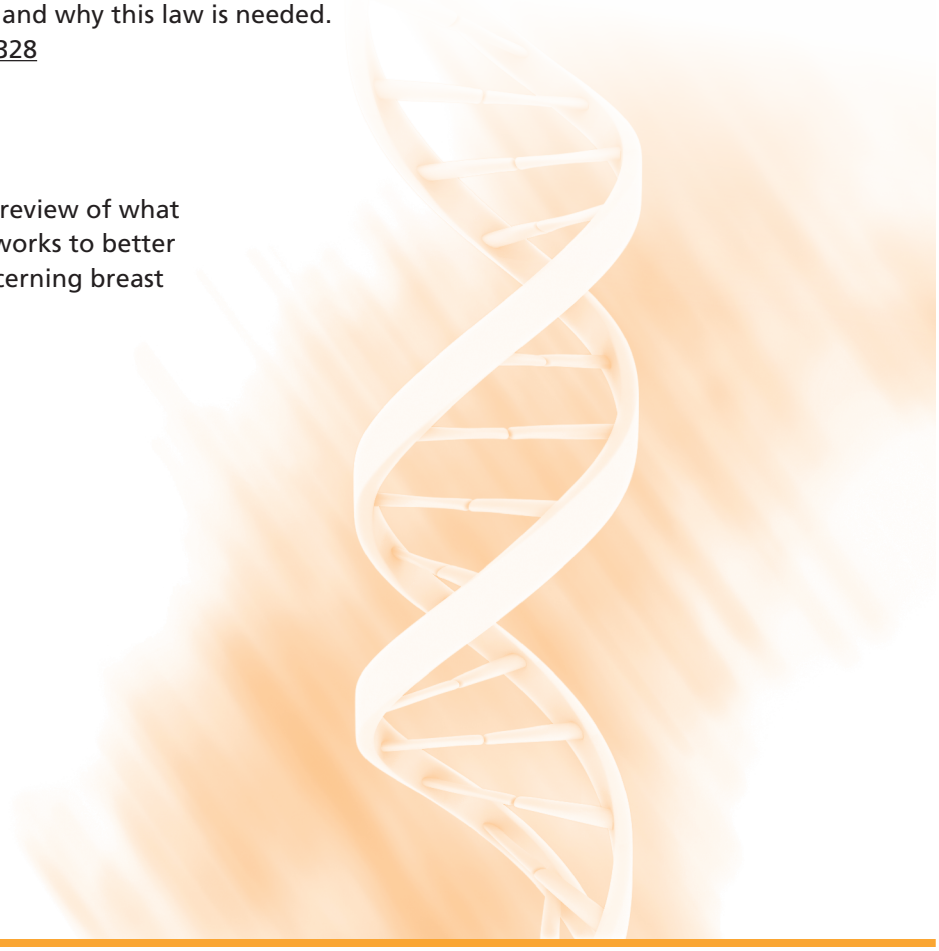
1. National Geographic, *Genographic: Permanent markers*. This website provides a lesson plan to further learning on genetic markers and the Genographic Project, which investigates where humans came from and how we populated the planet.
   http://www.nationalgeographic.com/xpeditions/lessons/09/g912/genographic2.html

2. National Human Genome Research Institute, *Genetic education resources for teachers*. This website provides various lesson plans and background information on genetics topics. Also use the link for *Online Genetics Education Resources* for further online resources.
   http://www.genome.gov/10005911#2

3. National Human Genome Research Institute, *Genetic Information Nondiscrimination Act of 2008*. This website briefly describes genetic discrimination, the United States' Genetic Information Nondiscrimination Act of 2008, and why this law is needed.
   http://www.genome.gov/10002328

Teacher Notes

1. Students may also need a brief review of what health insurance is and how it works to better understand the discussions concerning breast cancer and insurance coverage.



Part I: Introduction

Deoxyribonucleic acid (DNA) is the hereditary material that contains instructions that determine the way the parts of our body appear and function. DNA is the blueprint inside the nucleus of every cell that gives an organism its unique characteristics. For example, your DNA determines things like your eye color, hair color, and height.

Scientists use **DNA testing** to examine a person's DNA and determine the likelihood of that person getting a disease. A **genetic marker** is a section of DNA that indicates a greater likelihood that a person will get a disease. Having a genetic marker for a disease does not necessarily mean that a person definitely has or will get the genetic disease. Other factors, such as a person's environment, overall health, and nutrition may moderate the person's risk.

Knowledge of genetic markers may be associated with ethical dilemmas and personal risk. Some people are concerned that they may be mistreated if the private information from their DNA tests is misused. The genetic information information may be stolen, sold, or released to people who use the information unethically or illegally. The concern is that if a DNA test shows that a person has a genetic marker for a diesase, she may lose her job because of an employer's concern regarding her ability to adequately perform essential duties.

For example, a young woman has a DNA test and the results show that she has the genetic marker for Huntington's disease. Huntington's disease is a neurodegenerative disease that develops in mid-life. This means that the young woman would begin to lose muscle coordination and mental function around ages 30 to 40. If her employer discovers her condition, there may be concerns about her ability to perform her duties and the complications that will arise when the disease progresses. As a result, she may lose her job.

Another concern about the knowledge associated with genetic testing is about the loss of **health insurance** coverage. The prevention and treatment of a genetic disease for the lifetime of the young woman mentioned above would be very costly for an insurance agency. Therefore, if the agency learned of her condition, it is possible that the company would not continue to cover her expenses.

Would you be concerned about keeping your genetic information private if you had a genetic marker?

In today's module, you will read and discuss three different scenarios about DNA testing for genetic markers. You will learn about DNA testing to reveal genetic markers related to breast cancer, DNA testing of *in vitro* embryos before implantation in the uterus of the prospective mother, and DNA testing for genetic disesases that may be in a family.

Part II: Vocabulary

1. **DNA**: An acronym for deoxyribonucleic acid, which is a hereditary material that contains instructions for making proteins used in the body.
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5. **Health insurance**: Pays for all, or parts, of a person's health care bills.
6. **Mutation**: A change in the sequence of an organism's DNA.

Part III: Activities

Activity 1: What would you do?

You will now work in groups to discuss the following scenarios. Write down your group's responses to the questions provided. Your group does not have to agree on an answer. Each member of your group should write on their own paper. Use direct quotes and include details as you write.

Scenario #1: Would you become a "previvor?"

Read the following information aloud as a group. Ask group members or a teacher if there is a section that needs explanation.

BRCA1 and BRCA2 are names of specific human genes. BRCA1 and BRCA2 help repair DNA in the body if the DNA gets damaged, which may prevent cancer from forming. Some women have mutations, or changes, to BRCA1 and BRCA2. Mutations to BRCA1 and BRCA2 are genetic markers for cancer because the mutated gene may not be able to repair damaged DNA, and damaged DNA may lead to the formation of cancer.

The risk of an American woman developing breast cancer some time in her life is relatively low. Only 12 percent of women will develop breast cancer sometime in her life. In comparison, the risk of a woman with the BRCA1 and BRCA2 genetic marker developing breast cancer is much higher. Approximately 60 percent of women with the BRCA1 or BRCA2 genetic marker will develop breast cancer sometime in their life. Remember that not all women with the BRCA1 and BRCA2 genetic markers develop cancer. Other factors, including environment and family history of cancer, may also effect the likelihood of developing cancer.

There are a several options for women who learn they have the BRCA1 or BRCA2 genetic marker:

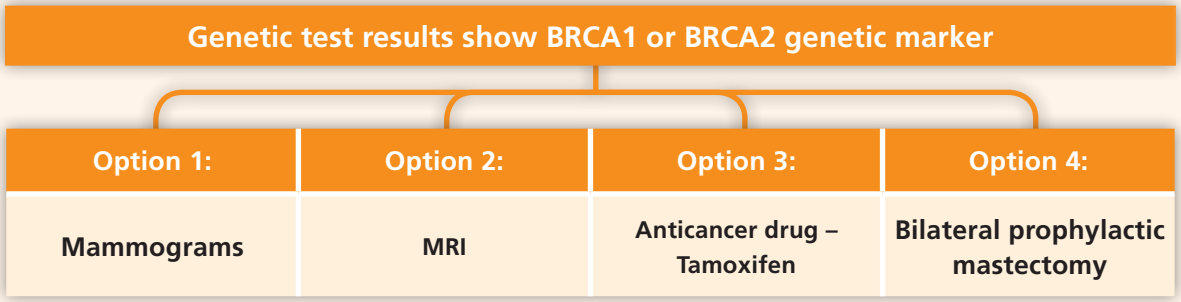
Option 1: Women with the BRCA1 or BRCA2 genetic marker may receive a mammogram at least once a year starting at an early age. A mammogram is an x-ray of breast tissue normally given to women 45 years of age and older. Mammograms may detect changes in breast tissue associated with cancer. Mammograms are normally not given to younger women because

younger women have denser tissue, which blocks some of what may be seen on an X-ray. Dense tissue in younger women makes it more difficult to detect changes in the breast tissue. Mammograms are thus less accurate in diagnosing cancer in younger women. Another reason mammograms are generally not given to younger women is that they use small doses of radiation. Radiation may increase risk for developing cancer because radiation may damage DNA. Exposure to radiation is a problem for women with the BRCA1 or BRCA2 mutation, since their bodies may be unable to repair damaged DNA, making the exposure to small doses of radiation more risky.

Option 2: Women with the BRCA1 or BRACA 2 genetic marker may choose to have an MRI scan of their breasts. An MRI is another technique for seeing inside tissue. It may be more accurate than a mammogram, and it uses no radiation. The drawbacks are that an MRI is more expensive and has a high incidence of false positives. A false positive means that the test says the person has cancer, but there is not really any cancer present. This may happen as often as one in five breast tissue MRIs.

Option 3: Women with the BRCA1 or BRACA 2 genetic marker may take tamoxifen, an anticancer drug. Tamoxifen is usually used to treat cancer, but it may also help prevent the development of cancer. Tamoxifen has been shown to be more effective against certain kinds of breast cancer. In 80 percent of the cases studied, women with the BRCA2 mutation were effectively treated with tamoxifen. Tamoxifen is less effective in the treatment of BRCA1. The drawback is that the use of tamoxifen as a preventative breast cancer treatement is still experimental; therefore, it is not known how effective anticancer drugs are at preventing cancer.

Option 4: A extreme option that some women with the BRCA1 or BRCA2 genetic marker may choose is a bilateral prophylactic mastectomy. A bilateral prophylactic mastectomy is the surgical removal of both breasts to prevent the risk of getting breast cancer. A bilateral prophylactic mastectomy is estimated to reduce the risk of getting breast cancer by 90 percent. Women who get a bilateral prophylactic mastectomy refer to themselves as "previvors." A previvor is someone who has not been diagnosed with cancer, but has an increased risk of cancer and takes actions to prevent the development of the cancer.



Think about the information you just read and discuss the following questions as a group. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did and what thoughts guided your decision process. There are no right or wrong answers to these questions.

1. If you were a woman with the the BRCA1 genetic marker, what would you do?

2. If you were a woman with the BRCA2 genetic marker, how would your answer to question #1 change? (Remember that the breast cancer that usually develops in people with BRCA2 is more effectively treated using tamoxifen.)

3. What would you do if you had no health insurance, which would pay all or part of the costs of surgery, mammograms, MRIs, and medicine?

Scenario #2: Embryo screening

Many couples who have difficulty conceiving a baby turn to *in vitro* fertilization (IVF). IVF is when an embryo is developed in a laboratory using reproductive cells of the couple or reproductive cells from other people.

Many embryos are screened for genetic markers that indicate certain diseases prior to implantation. This procedure is called Preimplantation Genetic Diagnosis (PGD). Based on the results of PGD, couples have the choice of whether or not to implant the embryo in the uterus of the prospective mother. With the discovery of new genetic markers, there is the potential for screening for many more diseases.

Recently, in Spain, couples were authorized to screen embryos for the mutated BRCA1 genetic marker for cancer. The reasoning behind the authorization is that there is a 50 percent chance that someone with the BRCA1 genetic marker for cancer will pass the BRCA1 genetic marker to their offspring. Offspring who inherit the BRCA1 genetic marker have a 60 percent chance of developing breast cancer. Screening embryos would allow couples to choose whether to have a child with a high risk of developing breast cancer. Some people choose not to screen their embryos because they believe it is unethical to choose their child's traits. They may wish not to know if their child is likely to be born with, or develop a disease. Furthermore, even if an embryo has a genetic marker for cancer the child will not necessarily get cancer. In addition, cancer treatment and prevention has advanced greatly in the past 20 years, therefore, a child born today may have more effective options to prevent breast cancer in their lifetime.

Think about the information you just read and discuss as a group the following questions. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did, and what thoughts guided your decision process. There is no right or wrong answer to these questions.

1. With the knowledge that an embryo's genes, including genetic markers for some diseases, may be detected by PGD, would you support embryo screening of IVF embryos before implantation? Why or why not?

2. If the technology was available to detect nonhealth-related aspects of the embryo prior to implantation, such as height and eye color, would you support people being allowed to screen their embryos for such traits? Why or why not?

Scenario #3: Would you get your DNA tested?

The cost of DNA testing is dropping dramatically. It is predicted that within 10 years, it will be inexpensive for a person to have all of their DNA screened for various genetic markers of disease.

Researchers have established strong, direct connections between some genetic markers and diseases. Researchers are still investigating other genetic markers, which seem to only indicate an increased likelihood a person will develop a disease. For example, Huntington disease affects the nerves and the brain, and is ultimately fatal. If a person has the genetic marker for Huntington's disease, the person will definitely get Hunington's disease. On the other hand, some genetic markers are linked only to an increased chance of developing a disease. For example, the BRCA1 and BRCA2 genetic marker indicates an increased risk for breast cancer, but not all women with the BRCA1 or BRCA2 genetic marker will develop cancer.

If doctors know your genetic markers, they may recommend medical options based on the information and you can make better decisions about your lifestyle and healthcare. For example, research has indicated that a genetic mutation may increase the risk of liver damage from a particular antibiotic. If your DNA test results show you have the genetic marker that increases the risk of liver damage from the antibiotic, you may avoid taking the antibiotic to lower your risk of liver damage.

Think about the information you just read, and discuss as a group the following questions. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did, and what thoughts guided your decision process. There are no right or wrong answers to these questions.

1. Would you have your DNA tested if you had very little or no known family history of genetic diseases?

2. If you had a genetic disease that would not develop until old age, would you want to know?

3. If your DNA test results showed that you have a genetic marker for a disease, what would you do differently in your life? Would you make different health choices? Have different life goals?

Part IV: Conclusion questions

Once your group has discussed their responses to the scenarios, take some time to think about today's module.

1. Why might a person want to get their DNA tested to check for a genetic marker for a disease? What are two possible advantages of knowing your genetic markers?

2. Why might a person choose to **not** get their DNA tested to check for genetic markers for a disease? What are two possible disadvantages of knowing your genetic markers?

Part V: Notes

Part I: Introduction

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Part III: Activities

Activity 1: What would you do?

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Scenario #1: Would you become a "previvor?"

Read the following information aloud as a group. Ask group members or a teacher if there is a section that needs explanation.

BRCA1 and BRCA2 are names of specific human genes. BRCA1 and BRCA2 help repair DNA in the body if the DNA gets damaged, which may prevent cancer from forming. Some women have mutations, or changes, to BRCA1 and BRCA2. Mutations to BRCA1 and BRCA2 are genetic markers for cancer because the mutated gene may not be able to repair damaged DNA, and damaged DNA may lead to the formation of cancer.

The risk of an American woman developing breast cancer some time in her life is relatively low. Only 12 percent of women will develop breast cancer sometime in her life. In comparison, the risk of a woman with the BRCA1 and BRCA2 genetic marker developing breast cancer is much higher. Approximately 60 percent of women with the BRCA1 or BRCA2 genetic marker will develop breast cancer sometime in their life. Remember that not all women with the BRCA1 and BRCA2 genetic markers develop cancer. Other factors, including environment and family history of cancer, may also effect the likelihood of developing cancer.

There are a several options for women who learn they have the BRCA1 or BRCA2 genetic marker:

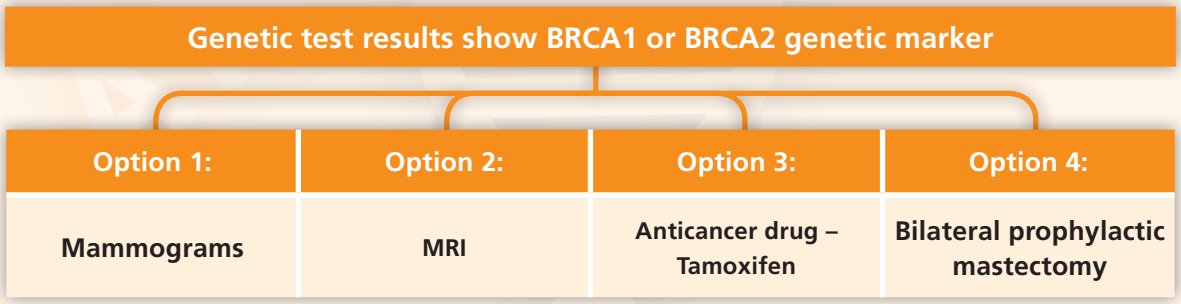
Option 1: Women with the BRCA1 or BRCA2 genetic marker may receive a mammogram at least once a year starting at an early age. A mammogram is an x-ray of breast tissue normally given to women 45 years of age and older. Mammograms may detect changes in breast tissue associated with cancer. Mammograms are normally not given to younger women because

younger women have denser tissue, which blocks some of what may be seen on an X-ray. Dense tissue in younger women makes it more difficult to detect changes in the breast tissue. Mammograms are thus less accurate in diagnosing cancer in younger women. Another reason mammograms are generally not given to younger women is that they use small doses of radiation. Radiation may increase risk for developing cancer because radiation may damage DNA. Exposure to radiation is a problem for women with the BRCA1 or BRCA2 mutation, since their bodies may be unable to repair damaged DNA, making the exposure to small doses of radiation more risky.

Option 2: Women with the BRCA1 or BRACA 2 genetic marker may choose to have an MRI scan of their breasts. An MRI is another technique for seeing inside tissue. It may be more accurate than a mammogram, and it uses no radiation. The drawbacks are that an MRI is more expensive and has a high incidence of false positives. A false positive means that the test says the person has cancer, but there is not really any cancer present. This may happen as often as one in five breast tissue MRIs.

Option 3: Women with the BRCA1 or BRACA 2 genetic marker may take tamoxifen, an anticancer drug. Tamoxifen is usually used to treat cancer, but it may also help prevent the development of cancer. Tamoxifen has been shown to be more effective against certain kinds of breast cancer. In 80 percent of the cases studied, women with the BRCA2 mutation were effectively treated with tamoxifen. Tamoxifen is less effective in the treatment of BRCA1. The drawback is that the use of tamoxifen as a preventative breast cancer treatement is still experimental; therefore, it is not known how effective anticancer drugs are at preventing cancer.

Option 4: A extreme option that some women with the BRCA1 or BRCA2 genetic marker may choose is a bilateral prophylactic mastectomy. A bilateral prophylactic mastectomy is the surgical removal of both breasts to prevent the risk of getting breast cancer. A bilateral prophylactic mastectomy is estimated to reduce the risk of getting breast cancer by 90 percent. Women who get a bilateral prophylactic mastectomy refer to themselves as "previvors." A previvor is someone who has not been diagnosed with cancer, but has an increased risk of cancer and takes actions to prevent the development of the cancer.



Think about the information you just read and discuss the following questions as a group. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did and what thoughts guided your decision process. There are no right or wrong answers to these questions.

1. If you were a woman with the the BRCA1 genetic marker, what would you do?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

2. If you were a woman with the BRCA2 genetic marker, how would your answer to question #1 change? (Remember that the breast cancer that usually develops in people with BRCA2 is more effectively treated using tamoxifen.)

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

3. What would you do if you had no health insurance, which would pay all or part of the costs of surgery, mammograms, MRIs, and medicine?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

Scenario #2: Embryo screening

Many couples who have difficulty conceiving a baby turn to *in vitro* fertilization (IVF). IVF is when an embryo is developed in a laboratory using reproductive cells of the couple or reproductive cells from other people.

Many embryos are screened for genetic markers that indicate certain diseases prior to implantation. This procedure is called Preimplantation Genetic Diagnosis (PGD). Based on the results of PGD, couples have the choice of whether or not to implant the embryo in the uterus of the prospective mother. With the discovery of new genetic markers, there is the potential for screening for many more diseases.

Recently, in Spain, couples were authorized to screen embryos for the mutated BRCA1 genetic marker for cancer. The reasoning behind the authorization is that there is a 50 percent chance that someone with the BRCA1 genetic marker for cancer will pass the BRCA1 genetic marker to their offspring. Offspring who inherit the BRCA1 genetic marker have a 60 percent chance of developing breast cancer. Screening embryos would allow couples to choose whether to have a child with a high risk of developing breast cancer. Some people choose not to screen their embryos because they believe it is unethical to choose their child's traits. They may wish not to know if their child is likely to be born with, or develop a disease. Furthermore, even if an embryo has a genetic marker for cancer the child will not necessarily get cancer. In addition, cancer treatment and prevention has advanced greatly in the past 20 years; therefore, a child born today may have more effective options to prevent breast cancer in their lifetime.

Think about the information you just read and discuss as a group the following questions. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did, and what thoughts guided your decision process. There is no right or wrong answer to these questions.

1. With the knowledge that an embryo's genes, including genetic markers for some diseases, may be detected by PGD, would you support embryo screening of IVF embryos before implantation? Why or why not?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

2. If the technology was available to detect nonhealth-related aspects of the embryo prior to implantation, such as height and eye color, would you support people being allowed to screen their embryos for such traits? Why or why not?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

Scenario #3: Would you get your DNA tested?

The cost of DNA testing is dropping dramatically. It is predicted that within 10 years, it will be inexpensive for a person to have all of their DNA screened for various genetic markers of disease.

Researchers have established strong, direct connections between some genetic markers and diseases. Researchers are still investigating other genetic markers, which seem to only indicate an increased likelihood a person will develop a disease. For example, Huntington disease affects the nerves and the brain, and is ultimately fatal. If a person has the genetic marker for Huntington's disease, the person will definitely get Hunington's disease. On the other hand, some genetic markers are linked only to an increased chance of developing a disease. For example, the BRCA1 and BRCA2 genetic marker indicates an increased risk for breast cancer, but not all women with the BRCA1 or BRCA2 genetic marker will develop cancer.

If doctors know your genetic markers, they may recommend medical options based on the information and you can make better decisions about your lifestyle and healthcare. For example, research has indicated that a genetic mutation may increase the risk of liver damage from a particular antibiotic. If your DNA test results show you have the genetic marker that increases the risk of liver damage from the antibiotic, you may avoid taking the antibiotic to lower your risk of liver damage.

Think about the information you just read, and discuss as a group the following questions. Write down the responses you hear from the group. Write down a response from every person in the group. The responses do not have to agree.

In your responses, explain why you answered the way you did, and what thoughts guided your decision process. There are no right or wrong answers to these questions.

1. Would you have your DNA tested if you had very little or no known family history of genetic diseases?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

2. If you had a genetic disease that would not develop until old age, would you want to know?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

3. If your DNA test results showed that you have a genetic marker for a disease, what would you do differently in your life? Would you make different health choices? Have different life goals?

The answer to this question is based on the opinion of each student. There is no right or wrong answer. Encourage students to support their thoughts and opinions with the information provided in the activities.

Part IV: Conclusion questions

Once your group has discussed their responses to the scenarios, take some time to think about today's module.

1. Why might a person want to get their DNA tested to check for a genetic marker for a disease? What are two possible advantages of knowing your genetic markers?

Two possible advantages of knowing your genetic markers are that you may take preventative measures to reduce the likelihood that you will develop a disease. For example, if you have a genetic marker for cancer, you may change your lifestyle to lower your risk of developing cancer and also obtain more frequent screenings in order to catch the disease early if it develops. In addition, if you know you have the marker for a genetic disease that develops late in life, you may be able to make different life choices, such as choosing not to have children.

2. Why might a person choose to **not** get their DNA tested to check for genetic markers for a disease? What are two possible disadvantages of knowing your genetic markers?

Two possible disadvantages of knowing your genetic markers are that you may worry needlessly about developing a disease that may never develop. In addition, based on your genetic marker, you may chose to have a drastic preventative procedure, such as a bilateral prophylactic mastectomy. There is also the risk that the information about your genetic marker may be shared.

Part V: Notes

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Solving and sharing the mysteries of genes

Module 7