## FUTU?ELAB+

### **LIVING EARTH**

*Genetic Detectives: Investigating Inherited Diseases* 

# Treating Inherited Disease

Developed in partnership with: Discovery Education

## In this Lesson Plan:

#### Print the Teacher Section $\rightarrow$

01 For Teachers				
Lesson Overview	1			
Make Connections!	3			
Pedagogical Framing	4			
Slides				
Day 1	5-7			
Day 2	8-9			
Day 3	10			
Day 4	11			
Day 5	12-15			
Day 6	16-17			
National Standards 18				

#### Print the Student Section $\rightarrow$ 🖶

02	Student Resources			
Genetic Test Report Critique and Feedback				
Treatr	nent for Inherited Diseases			
	Mini-Session 1 Preventive Treatment Methods	2-3		
	Mini-Session 2 Reactive Treatments for Methods	4-5		
Inheri	ted Disease Treatments Mini-Session			
	Part 1 Preventive Treatments	6-7		
	Part 2 Reactive Treatments	8-9		
Treatr	Treatment Options for My Patient			
	Preventive Treatment Option 1	10		
	Preventive Treatment Option 2	11		
	Reactive Treatment Option 1	12		
	Reactive Treatment Option 2	13		
Bioethics of My Work as a Genetics Counselor				
Close Reading Protocol Activity				



**Cover Image** Genetic research, pipetting into a test tube in front of a DNA autoradiogram This document is separated into two sections, For Teachers [T] and Student Resources [S], which can be printed independently.

Select the appropriate printer icon above to print either section in its entirety.

Follow the tips below in the Range field of your Print panel to print single pages or page ranges:

Single Pages (use a comma): T3, T6

Page Range (use a hyphen): T3-T6

### **Treatments for Our Patient's Disease**

#### DRIVING QUESTION

How do you counsel patients on their risk of genetic disease while considering their health literacy?

#### OVERVIEW

In this lesson, students identify treatment options for their patient's inherited disease. They begin by researching a variety of preventive and reactive treatments and writing the treatment options into their **Genetic Test Report**. Students learn about CRISPR genome editing, preimplantation genetic testing, gene therapy, and other disease-specific treatments. Additionally, students consider the ethical dilemmas of gene editing from the perspectives of patients and genetic counselors. They must be mindful of these bioethical concerns as they develop their Genetic Testing Reports.

#### ACTIVITY DURATION

Six days

#### **ESSENTIAL QUESTIONS**

Can inherited diseases be prevented?

How can inherited diseases be treated?

What ethical and moral dilemmas do genetic counselors and patients face when dealing with an inherited disease?

#### OBJECTIVES

Students will be able to:

**Discover** how gene therapy treats inherited disease.

**Explore** CRISPR genome editing and **understand** how preimplantation genetic testing can prevent inherited diseases from being passed down to offspring.

**Discuss** the bioethics related to the treatment methods of inherited disease.

**Consider** the ethical dilemmas associated with the work genetic counselors do with patients and the impact they have on communicating information with their patient.

Day 1	Day 2	Day 3	Day 4	Day 5	Day 6
Complete the feedback protocol on the test.	Begin self-guided mini-sessions to learn about treatments for inherited diseases.	Complete self- guided mini- sessions about treatments for inherited diseases.	Discover social and ethical dilemmas surrounding gene editing. Conduct research on reactive and preventive treatment for inherited diseases.	Learn about the ethical dilemmas surrounding gene editing. Consider bioethics through the perspectives of genetic counselors and patients.	Develop the "Next Steps" Section of the <b>Genetic Test</b> <b>Report</b> for their patient.
				XS	5

STUDENT TASKS

## **MAKE CONNECTIONS!**

How does this connect to the larger unit storyline?

Students identify the treatment options for their patients and use this information to further develop their *Genetic Test Report*.

Genetic engineers, sometimes known as bioengineers, develop methods for identifying and treating disorders and diseases like sickle cell caused by DNA mutations.

Bone marrow transplants are the most common treatment for sickle-cell disease.

## *How does this connect to careers?*

*Bioethicists* help doctors make complex decisions around the moral elements of health care. Bioethicists are highly involved in making decisions around appropriate uses of gene editing technology.

*Disability advocates* promote awareness about disabilities and teach others how to support disabled people. They may work in the law, helping disabled people fight discrimination. They may work in nonprofits that provide support services for disabled people or in lobbying organizations that try to persuade government officials to fund disability research and treatment.

*Regulatory affairs specialists* help companies ensure that they are in compliance with federal, state, local, and industry regulations. In a clinical setting, regulatory affairs professionals help new therapies navigate government approval processes.

**Occupational therapists** help people with disabilities develop skills to complete day-to-day activities. They help patients with a wide array of conditions to achieve independence and manage difficult aspects of their diseases.

*Hematologists* are doctors who specialize in blood disorders.

A *genetic enginee*r is professionally responsible for conducting a thorough study of genes present in living forms—human beings, plants, animals, and even microorganisms. They are sometimes referred to as biomedical engineers.

*Pathologists* often work with genetic engineers by examining cells and tissues to aid in diagnosis and treatment.

## *How does this connect to our world?*

This lesson gives students an opportunity to research genetic engineering and new technologies that are pioneering the fight against diseases such as Sickle Cell anemia. Sickle cell disease (SCD) is the most common inherited blood-cell related disorder worldwide. SCD affects more than 100,000 Americans and occurs in about 1 in 500 African-American births and in 1 in every 1,000 to 1,400 Hispanic-American births.<sup>1</sup>

Students consider their own feelings when examining the bioethics connected to genetic counseling, the treatment of inherited diseases, and decisions patients and families face when dealing with an inherited disease.

<sup>1</sup> "Did You Know Sickle Cell Has Many Faces?," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, September 1, 2020).

## **Pedagogical Framing**

Instructional materials are designed to meet national education and industry standards to focus on in-demand skills needed across the full product development life cycle from molecule to medicine—which will also expose students and educators to the breadth of education and career pathways across biotechnology.

Through this collection, educators are equipped with strategies to engage students from diverse racial, ethnic, and cultural groups, providing them with quality, equitable, and liberating educational experiences that validate and affirm student identity.

Units are designed to be problembased and focus on workforce skill development to empower students with the knowledge and tools to be the change in reducing health disparities in communities.



#### SOCIAL-EMOTIONAL LEARNING

This lesson encourages students to practice self-management skills while pursuing research into treatment options and other tasks of a genetic counselor. They practice social awareness by working collaboratively to better understand preventative and reactive treatments for inherited diseases and discuss the pros and cons of various treatment options. Students demonstrate empathy while they examine ethical issues associated with gene editing, being mindful of these bioethical concerns as they continue developing their Genetic Testing Report.

#### CULTURALLY AND LINGUISTICALLY RESPONSIVE INSTRUCTION

This lesson applies culturally and linguistically responsive instruction to research and discussion about the role of a genetic counselor. These professionals often face social and ethical dilemmas when exploring treatment options that include genetic therapy. The lesson offers opportunities for creating empathetic, culturally and linguistically responsive, and socially aware presentation options, treatment choices, and healthcare information to share with patients. This increases self and cultural validation, while bridging the content from scholastic research to the reality of diverse communities.

#### ADVANCING INCLUSIVE RESEARCH

Medical professionals, scientists, and genetic counselors often face social and ethical dilemmas in their work. Genetic counselors must be able to recognize those dilemmas and their own personal bias in order to ensure that they communicate the best options available to their patients. When genetic counselors are culturally competent and empathetic, they help increase their patient's health literacy and help eliminate barriers surrounding their treatment options. These trust-building practices help to build relationships with communities that have historically been mistreated by established medicine.

#### COMPUTATIONAL THINKING PRACTICES

Genetic engineers use the computational thinking strategies of abstraction and decomposition in their work with CRISPR. By utilizing the strategy of abstraction, these professionals can disregard irrelevant sections of DNA and hone in on a specific gene. Through decomposition, engineers break down the DNA sequence into component parts and make a precise "snip" with an enzyme that allows them to add or delete genetic material. In this lesson, students learn about gene editing as a potential therapy for genetic diseases. They also use the computational thinking strategies of collecting and analyzing data to identify criteria for success and create a plan for receiving and giving feedback.

#### CONNECTION TO THE PRODUCT LIFE CYCLE

Gene editing therapies exist in the Manufacturing stage of the product life cycle, where they are produced and distributed on a mass scale. These new therapies raise complex bioethical questions and are subject to the deliberations of government regulatory agencies.

#### INDUSTRY AND CAREER CONNECTION

As students learn about genetic adaptations to diseases like malaria, they can see how some *mutations provide advantageous* traits that eventually become disadvantageous. Genetic engineers and bioethicists must keep this principle in mind as they consider designing treatments for the diseases of the future. They must consider questions such as "what could the ripple effect of this genetic change be?" and "is having some maladaptive genetic traits ultimately better for diversity?"



The image shows a blood smear from patients with anemia and abnormal red blood cells.

### Slides 1–18

Sli	des 1	-18
Stu	dents	consider evolutionary connections and advantages to inherited diseases.
1		Ask students if they believe there may be benefits to some mutations or diseases. How do they believe they evolved over time? What would cause these changes, mutations, and/or adaptations in a population?
2		Using the instructional strategy <i>Pause and Play</i> , allow students to view this <i>TED-ed</i> video: How This Disease Changes the Shape of Your Cells, by Amber M. Yates.
3		Post the questions below for students to answer as they view the video. Make sure that you pause throughout the video, allowing students to record their answers.
	a.	What is the environmental factor that caused this genetic mutation?
	b.	What is the evolutionary advantage of having only one sickle cell trait?
	c.	What occurs when an individual inherits the sickle cell trait from both parents?
	d.	What region of the world is greatly impacted by sickle cell disease?
4		Review answers with students. Explain that the sickle cell trait is not the only inherited blood disorder that evolved in order to protect populations from malaria, a sometimes fatal disease caused by a mosquito parasite.
5		<i>Thalassemia</i> (an inherited blood disorder that lowers hemoglobin and causes fewer red blood cells), <i>G6PD</i> (a genetic disorder affecting mainly males that causes a decrease in red blood cells) and <i>Ovalocytosis</i> (an inherited red blood cell disorder) have all evolved in response to the selective pressures of malaria.
6		Ask students why <i>malaria</i> alone would cause so many different mutations and inherited diseases. ( <i>Answer</i> : Malaria is one of the world's oldest infections that causes death and illness. Due to malaria's devastating effects, humans have evolved adaptive traits to survive).
7		Have a class discussion, using the culturally responsive participation protocol <i>Numbered Heads Together</i> , around the following questions:
	a.	What is an evolutionary defense for genetic diseases that explains natural selection? (Most genetic diseases that are not fatal in childhood let humans live long enough to reproduce.)

#### COMPUTATIONAL THINKING IN ACTION

Here, students see how genetic counselors use the computational thinking strategy of finding patterns to identify characteristics that might make someone susceptible to certain genetic diseases.

### Slides 1–20

- **b.** Why is it important for genetic counselors to know which inherited diseases are common in specific regions of the world?
- c. Why is it important to know the ancestry of your patients?
- **d.** Why would it be helpful to share information about natural selection, inherited diseases in specific regions, and ancestry with your patient?
- **e.** How will information about natural selection, inherited diseases in specific regions, and ancestry affect how you create your Genetic Test Report?
- 8 Have students dig deeper into adaptation and gene expression by having them independently complete the *Close Reading Protocol Activity* capture sheet.

#### Slides 19-20

Students generate criteria of success for their Genetic Test Report.

**Prepare in Advance:** Use student exit tickets from the last day of Lesson 3 to create a list of characteristics of effective genetic test reports.

1		Ask students if there Is anything they want to add to this list.
2		Project the <i>Genetic Test Report example</i> for students to view.
3		Pair students up to read <i>the abstract</i> with a partner. Have partners actively read the article out loud using the following directions:
	a.	Take turns reading each section aloud with your partner.
	b.	As you read, add the following marks to the paper:
		<ul> <li>Put a circle around any word you do not understand.</li> <li>Put a + sign next to an idea you think would be good to use for our genetic test reports.</li> </ul>
4		After reading the abstract, have students review the Criteria for Success anchor chart. Based on what we know now, how should we change our criteria?
5		In their groups, have students identify three or four criteria for developing an effective genetic test report for their patient.
6		Have groups share their ideas with the class. List the ideas. With students' help, identify three or four effective criteria of success and record them on the anchor chart. Tell students that the anchor chart will be used to help them give feedback to one another on their reports.

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#### COMPUTATIONAL THINKING IN ACTION

As students edit their criteria, they are using the computational thinking strategy of collecting data. This strategy involves designing questions and lookfors that collect data in a format that makes it easy to analyze. Students also practice the computational thinking strategy of analyzing data as they review the importance of giving and receiving feedback.

Continued

#### INDUSTRY & CAREER CONNECTION

As students practice designing criteria and feedback structures, they are practicing skills used by occupational therapists every day. These professionals rely on collecting feedback in many forms (patient experience, physical testing, etc.) in order to know if their treatments are making progress. An important part of occupational therapy is knowing how to deliver feedback to patients in a way that is kind and motivating.



## Slide 21-22

#### Slide 21

Students begin to share feedback on their Genetic Test Reports.

- 1 Pair students to present and share feedback on their **Genetic Test Report**. Ensure that partners have reports on different inherited diseases.
- 2 Ask students to share aloud their ideas on the following prompts:
  - **a.** Why is it important to revise your report?
  - **b.** Why is feedback important?
  - c. How do you give effective feedback?
- 3 With the final prompt, develop three criteria of effective feedback:
  - **a.** Feedback is useful.
  - **b.** Feedback is specific.
  - **c.** Feedback is given in a kind manner.

Tell students the way to make their feedback specific and useful is to use the criteria of success the class developed on the anchor chart and to give specific examples in the genetic test report they are critiquing.

4 Have students take part in the *Charrette Protocol* and the *Genetic Test Report Critique and Feedback* capture sheet.

#### Slide 22

Students consider the next steps and content for the project.

- 1 At the end of the class debrief, have students write a quick response to the following exit ticket prompt: "Thinking about the next phase of our project where you will, as a genetic counselor, need to communicate the treatment options for the inherited disease your patient has been diagnosed with. What will you need to learn about first in order to prepare to do this work?"
- 2 Record responses for Day 2.

## **Slides 23–26**

#### Slides 23-25

Students consider what they already know about medical treatments for illnesses.

- 1 **Prepare ahead of time:** Use student exit tickets from Day 1 of this lesson to identify the N2K Questions that are connected to communicating inherited disease treatment options. Add these to the N2K list prior to class.
  - **a.** Ask students if there are any other questions they want to add to this list.
  - **b.** Have students complete the first part of the *3-2-1 Bridge* thinking routine using the topic of medical treatment.
    - Students write down three thoughts or ideas, two questions, and come up with one metaphor or simile about medicine treatment.
    - Once complete, have a few students share aloud their examples.
    - Students will complete Part 2 of the thinking routine at the beginning of class on Day 6.

#### Slide 26

1

Students form their mini-session groups.

**Prepare in advance:** Prepare materials in the two mini-sessions: Preventive and Reactive Treatments.

**Teacher Note** > *As students move through the mini-sessions ask them to consider the multiple careers that are associated with patient research, development of treatments, diagnosis, patient education, and patient treatment, and patient care. Remind them that a genetic counselor does not work alone and is supported by the work of many diverse scientists and medical workers that are dedicated to improving the lives of patients.* 

- In five locations around the room, post signs with the name of each of the genetic diseases. Tell students to go to their sign. Then have students self-select groups of three or four within their inherited disease group.
- 2 Assign groups to Mini-Session 1 or Mini-Session 2. Remind students that they will have an opportunity to visit the other session.
- 3 Inform students that Mini-Session 1 represents preventive treatments for inherited diseases and Mini-station 2 represents reactive treatments.
- 4 Have students visit the stations and begin their research.

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#### COMPUTATIONAL THINKING IN ACTION

The 3-2-1 Bridge structure gives students hands-on experience with the computational thinking strategy of abstraction, which involves reviewing data and focusing only on the essential information.

#### INDUSTRY & CAREER CONNECTION

Invite students to think about the related careers of hematology and pathology. These professionals collect blood and tissue samples that help identify markers of disease and share that information with the patient.



### Day 2 Continued

#### COMPUTATIONAL THINKING IN ACTION

As students work through the mini-sessions, they are walking through an algorithm that is designed to teach them about treatments for inherited diseases. The facilitator's role is to help students follow the steps of the algorithm accurately.

## Slides 27

#### Slide 27

Students move through the first round of a self-guided mini-session on inherited disease treatments.

1 Inform students that they are going to facilitate their learning and the learning of their group members during these mini-sessions. Explain to students: "As a group, you are going to be responsible for moving each other through the steps of the mini-session. To do this, one person in your group needs to be the facilitator and one person the time keeper. The facilitator is in charge of leading the group through each step of the session. The time keeper is in charge of making sure the group does not go under or above the time given for each step." 2 Have groups select who will be the facilitator and who will be the time keeper. Tell students that they will alternate who takes on these roles when they complete the second session tomorrow. 3 Pass out Treatment for Inherited Diseases Mini-Sessions instructions and Inherited Disease Treatments Mini-Session capture sheet. Review the documents with students. Explain that the information they add to this capture sheet will be used 4 to develop the "Next Steps" section of their Genetic Test Report, so it is vital that they take detailed and clear notes. 5 Allow students to begin the work in their mini-session.



## **Slides 28–29**

Slide 28	
Students f	inish the mini-sessions on inherited disease treatments.
1	Have students visit the mini-session they did not complete previously.
2	Have students identify a different facilitator and time keeper for their group.
3	As students work through the mini-sessions, have them take notes in their <i>Inherited Disease Treatments Mini-Session</i> capture sheet.



## Slides 30-32

#### Slide 30-31

Students conduct research on the specific treatments for their inherited disease.

1	Have students remain in their mini-session groups.
2	Tell students they are now going to take on the role of a genetic counselor and research the best treatments to recommend for their patients.
3	Have the groups divide into two groups—one group will research and identify the preventive options they would recommend, while the other group identifies the reactive treatments they would recommend.
4	To do this work, pass out the <i>Treatment Options for My Patient</i> capture sheet for students to collect their information.
5	Review the document with students and show them how to use the <i>Inherited Disease Treatment Online Resources</i> to complete their research.
6	Inform students that they are doing this research to recommend treatment methods for their patient and the work they do in this section will be used to complete the "Next Steps" section of their <b>Genetic Test Report</b> .
7	Let students research until 15 minutes remain in class time.

### Slide 32

Students return to their larger group that is researching the same inherited disease.

1	Have students present their findings to the other people in the group.
2	After listening to the recommended treatment options being identified, they complete the other treatment section of their <i>Treatment Options for My Patient capture</i> sheet.

## Day 5 Slides 33-41

#### Slides 33-37

Social Dilemma in Gene Therapy: Whole Group Activity

**Teacher Note** > Introduce the topic of social dilemmas associated with gene therapy. Please be aware that some students may have cultural and religious views of gene editing and may be sensitive to this topic.

1		Have students watch the TED Talk Video: <i>Sickle Cell Disease—A battle for equality, justice, and respect</i>
2		Students will use the instructional strategy <i>Pause and Play</i> to give them time for response and reflection. Post the questions below for students to answer, as they watch the video. Pause frequently, giving students the opportunity to respond to questions:
	a.	Which social justice issues affect patients with Sickle Cell Anemia?
	b.	What therapies are available for Sickle Cell patients?
	c.	How can we improve outcomes for patients with Sickle Cell Anemia?

### Slides 37-41

Ethical Dilemma in Gene Therapy: Whole Group Activity

**Teacher Note** > *This is a complex topic that requires* <u>research</u> and requires thoughtful facilitation.





Continued

#### INDUSTRY AND CAREER CONNECTION

As students discuss ethical and social dilemmas in gene therapy, they must consider the important voices of disability rights advocates. These professionals work in law and nonprofit settings and represent the rights of disabled people. They advocate for awareness and treatment for genetic disease, and many disability rights specialists work on battling stigma and creating social acceptance for different forms of disability.

#### **INDUSTRY & CAREER CONNECTION**

Regulatory affairs specialists work with companies to make sure they are abiding by all federal and state regulations. This includes ensuring compliance with laws such as the Americans with Disabilities Act (ADA) passed in 1990. Regulatory affairs specialists also play an important role in helping new treatments move through the government approval process.

### Slides 42-50

- c. What are the societal and ethical dilemmas associated with CRISPR?
- d. What will CRISPR technology allow us to do in the future?

#### Slides 42-50

Whole Group Discussion: Ethical and Social Dilemmas in Gene Therapy

**Teacher Note** > Have groups consider various ethical and social dilemmas. This is a complex conversation that should be handled with empathy and respect. Students should be made aware that the goal is to listen to and understand other perspectives on these issues, not to argue the merits of their own. Explain that when seeking to understand perspective, that does not mean that everyone needs to agree on specific perspectives. By challenging yourself to seek the perspectives of others, you often challenge your own and gain a better understanding of various situations. This is vital to working within the medical pathway of genetic science and working with diverse patient populations. Encourage students to be respectful of their classmates' opinions and to set a tone where ideas can be comfortably shared. Have groups consider the following ethical and social dilemmas:

- **a.** People should be allowed to use gene therapy to enhance basic human traits such as height, intelligence, or athletic ability.
- **b.** The government should play a role in regulating which types of gene therapies are allowed in our country.
- **c.** Because gene therapy will likely increase many health disparities, it should be accessible to all, not just those who can afford it.
- **d.** Germline editing should not be allowed because patients cannot truly make an informed consent because we do not know what the impact on future generations will be.
- e. Parents should be able to decide which traits constitute a disability or disorder.
- **f.** Religious considerations should be taken into account when deciding whether a disorder or disability is considered for gene therapy.
- **g.** Somatic editing should be allowed because it only affects the individual seeking treatment and not future generations.
- 1 To consider these dilemmas, have students use this variation of the Culturally and Linguistically Diverse strategy: *Vote With Your Feet*.

### Day 5 Continued

## Slides 42-56

2

Explain to students that there is an imaginary line that runs through the classroom. The line represents a continuum. Designate which side of that continuum represents "strongly disagree" and which side represents "strongly agree." Explain to students that they will have the opportunity to decide where to stand on the continuum, between the two points. After each prompt, students will silently move to a point on the "line" to represent their response to each prompt. Give students the opportunity to discuss their point of view with a shoulder partner. Afterwards, ask students to volunteer to share their ideas with the whole group. After all prompts have been shared, have students return to their seats.

- 3 When students are seated within their groups, ask them to consider the following prompts:
  - a. What is the difference between a social and an ethical dilemma?
  - **b.** How are these types of dilemmas connected to your work as a genetic counselor?
  - **c.** Look at the list of Pros and Cons you listed in the *Inherited Disease Treatments Mini-Sessions* capture sheet. Explain. Are any related to ethical or social dilemmas?
- 4 **Prepare in advance**: Create an anchor chart with two columns titled "Ethical Dilemma & Social Dilemma."
  - **a.** As students share the dilemmas from their Pro and Con list, write them onto an anchor chart. Prompt students to identify the category where their example should be placed. Ask students to explain why they think their example is either an ethical or social dilemma.
  - **b.** Have students share any other dilemmas they believe are connected to their role as a genetic counselor. Add examples to the anchor chart.

#### Slides 51-56

1

Students consider the main dilemmas they and their patients face.

Tell students they will work together in their groups to identify and discuss the main dilemmas they face as genetic counselors in their work with their patients. Also, have them discuss the main dilemmas they anticipate their patients will face when they read the **Genetic Test Report**.



### Day 5 Continued

#### COMPUTATIONAL THINKING IN ACTION

Here, students examine the role of personal bias in communicating with their patient. This relates to the computational thinking strategy of analyzing data, which involves being cognizant of any types of bias that might impact results.

### **Slides 51–56**

- 2 To do this, have students follow the steps in the *Bioethics of my Work as a Genetic Counselor* capture sheet.
- 3 Review the document with students. Have groups select their Facilitator and their Clock Keeper. When ready, let the groups begin the activity described in the document.
- 4 Have groups focus on perspectives and reactions that come up as they discuss the following prompts:
  - **a.** Should genetic counselors tell their patients which treatment options they should choose?
  - **b.** How does the ethical dilemma you face as a genetic counselor impact how you communicate with your patient?
  - c. How will this impact how you create your Genetic Test Report?
  - **d.** How do you ensure your personal bias does not affect the way you counsel and communicate with your patient?

6

As an exit ticket, have students respond to the following prompt with a neighbor: If you were a patient receiving genetic counseling for this disease, which treatment option would you choose? Why?

### **Slides 57–59**

#### Slides 57-58

Students complete the 3-2-1 Bridge thinking routine about medicine. (10 minutes)

1 Have students complete the second of the 3-2-1 Bridge thinking protocol they started on Day 1 of this lesson using the following prompts:

Using what you learned about the medical treatment for inherited disease, write your new responses:

- a. What are three new thoughts or ideas you have about medicine?
- **b.** What are two new questions you have about medicine?
- c. What is a new metaphor or simile you can make about medicine?
- **d.** Now, create your bridge between your first response and today's response. Explain how your new response connects to your initial response.
- 2 Have students use the stand-and-share discussion protocol to volunteer how their thoughts might have changed around their responses to medicine in the 3-2-1 Bridge activity.

#### Slide 59

Students develop their Genetic Test Report. (30 minutes)

1		Have students take out their <i>Treatment Options for My Patient</i> capture sheet.
2		Tell students they are going to identify and describe which treatment options they have chosen for their patient.
3		These treatment options will go into the "Next Steps" section of their report.
4		Have them include the following information:
	a.	one or two preventive treatment options
	b.	one or two reactive treatment options





### Slides 59-60

c.

		treatment option that includes:
		<ul><li>what the treatment is</li><li>how the treatment works</li><li>why the treatment helps</li></ul>
5		In order to create this information for their patients, students need to include ideas that were identified in the narrative in Lesson 3 on the anchor chart. The ideas include:
		<ul> <li>graphics</li> <li>graphs</li> <li>infographics</li> <li>a combination of these ideas</li> </ul>
6		For each treatment option, have students include one or two ideas from the anchor chart to ensure the information is easy to understand for their patient.
7		Have students work on developing the "Next Steps" section of their <b>Genetic Test Report</b> .
Slie	de 60	
Debi	rief Le	esson 4 with students. (5 minutes)
1		For the class discussion around the prompts below, have students first discuss in their groups, and then have groups share aloud one item from their group discussion.
2		Use the following prompts to facilitate a class debrief:
	a.	Take a look at our N2K questions. Which questions can we answer now based on the work we have done so far?
	b.	What new questions do you have that we need to add to our N2K questions?
	c.	Other questions to consider or discuss:
		• What do you think the patient will need to consider when deciding

For each treatment option make sure to include a description for each

3 At the end of the class debrief, give students the following exit ticket prompt: "In the next phase of our project you will need to communicate as a genetic counselor to share a **Genetic Test Report** with your patient. What do you think you will need to learn about next, in order to do that work?"

which treatment option to choose?

## National Standards

#### **Next Generation Science Standards**

Science and Engineering Practices (SEP)

#### Practice 6 Analyzing and Interpreting Data

Construct an explanation based on valid and reliable evidence obtained from a variety of sources (including students' own investigations, models, theories, simulations, peer review) and the assumption that theories and laws that describe the natural world operate today as they did in the past and will continue to do so in the future.

#### Disciplinary Core Ideas (DCI)

#### LS3.B | Variation of Traits

In sexual reproduction, chromosomes can sometimes swap sections during the process of meiosis (cell division), thereby creating new genetic combinations and thus more genetic variation. Although DNA replication is tightly regulated and remarkably accurate, errors do occur and result in mutations, which are also a source of genetic variation. Environmental factors can also cause mutations in genes, and viable mutations are inherited.

#### LS4.B | Natural Selection

Natural selection occurs only if there is both (1) variation in the genetic information between organisms in a population and (2) variation in the expression of that genetic information—that is, trait variation—that leads to differences in performance among individuals. The traits that positively affect survival are more likely to be reproduced, and thus are more common in the population.

#### LS4.C | Adaptation

Natural selection leads to adaptation, that is, to a population dominated by organisms that are anatomically, behaviorally, and physiologically well suited to survive and reproduce in a specific environment. That is, the differential survival and reproduction of organisms in a population that have an advantageous heritable trait leads to an increase in the proportion of individuals in future generations that have the trait and to a decrease in the proportion of individuals that do not.

Adaptation also means that the distribution of traits in a population can change when conditions change.

#### Crosscutting Concepts (CC)

#### **Cause and Effect**

Empirical evidence is required to differentiate between cause and correlation and make claims about specific causes and effects.



#### **Genetic Test Report Critique and Feedback**

#### Directions

Work in pairs to present and share feedback on your **Genetic Test Report**. Remember, effective feedback is useful, specific, and given in a kind manner.

1. Feedback From My Partner

2. My Feedback To My Partner

#### **Treatment for Inherited Diseases, Mini-Session 1** *Preventive Treatment Methods*

#### Directions

In this session, you will explore types of preventive treatment for inherited diseases. This is a guided group activity. In your group, identify who will facilitate and who will keep track of time.

#### Roles

*Facilitator* Reads the directions for each step and leads the group through the procedure for each step.

*Clock Keeper* Keeps track of the time for each step. This person makes sure the group does not go under or over time for each step.

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Steps		Description	Duration
Think and Discuss	1	Individually, respond to the prompt: "What are some different ways you can help prevent illness?"	5 minutes
	2	With your group, discuss the following prompt: "How is trying to prevent inherited diseases different from trying to prevent getting sick from something like the flu or a cold?"	
Brainstorm	1	Based on what you have learned so far, create a list of ideas that can help prevent patients from getting an inherited disease.	5 minutes

### Treatment for Inherited Diseases, Mini-Session 1

Preventive Treatment Methods

Continued

Steps		Description	Duration
Decide	1	With your group, divide the resources below. You can work with a partner to review one of the resources that describes preventive treatments for inherited diseases together.	1 minute
	2	You will be responsible for teaching the other students about the information you researched in the next step of this mini-session.	
	+	Preventive Treatment Methods	
	а	CRISPR is a Revolutionary Gene-editing Tool, but it's Not Without Risks	
	b	What is Preimplantation Genetic Testing?	
	с	How Preimplantation Genetic Testing Works	
	d	Justice in CRISPR/Cas9 Research and Clinical Applications	
Read	1	Collect the following information about your resource to share with the group:	15 minutes
		What is the treatment called?	
		Why does it help prevent the inherited disease?	
		How does it work?	
	2	As you read, record the information in your Inherited Disease Treatments Mini-Session capture sheet.	
Share	1	Share the information with your group. Use the images in your resource to help teach other group members about your treatment.	12 minute
	2	As group members share their information, take notes in your <i>Inherited Disease Treatments Mini-Session</i> capture sheet.	
Discuss	1	Based on what you have learned about each preventive treatment, discuss the following prompt: "What are the pros and cons for this type of treatment?"	5 minutes

#### **Treatment for Inherited Diseases, Mini-Session 2** *Reactive Treatments for Methods*

#### Directions

In this session, you will explore types of treatment for patients diagnosed with inherited diseases. This is a guided group activity. In your group, identify who will facilitate and who will keep track of time.

#### Roles

*Facilitator* Reads the directions for each step and leads the group through the procedure for each step.

*Clock Keeper* Keeps track of the time for each step. This person makes sure the group does not go under or over time for each step.

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Description	Duration
1 Individually, respond to the prompt in your capture sheet: "When you get sick, what different things do you do to treat your illness?"	5 minutes
2 With your group, discuss the following prompt: "How is trying to treat an inherited disease similar and different from treating an illness like a flu or cold?"	
1 Based on what you have learned so far about the inherited disease, create list of ideas that you think would be helpful for your patient.	a 5 minutes
1 With your group, divide the resources below. Work with a partner to review of the resources that describes preventive treatments for inherited diseases	one 1 minute
2 You will be responsible for teaching the other group members about the preventive treatments in the next step of this mini-session.	
+ Reactive Treatment Methods	
a What is Gene Therapy	
b Approaches to Gene Therapy	
c Bone Marrow Transplant	
	<ol> <li>Individually, respond to the prompt in your capture sheet: "When you get sick, what different things do you do to treat your illness?"</li> <li>With your group, discuss the following prompt: "How is trying to treat an inherited disease similar and different from treating an illness like a flu or cold?"</li> <li>Based on what you have learned so far about the inherited disease, create list of ideas that you think would be helpful for your patient.</li> <li>With your group, divide the resources below. Work with a partner to review of the resources that describes preventive treatments for inherited diseases</li> <li>You will be responsible for teaching the other group members about the preventive treatments in the next step of this mini-session.</li> <li>Reactive Treatment Methods</li> <li>What is Gene Therapy</li> <li>Approaches to Gene Therapy</li> <li>Bone Marrow Transplant</li> <li>Different between the state of the</li></ol>

### Treatment for Inherited Diseases, Mini-Session 2

Reactive Treatments for Methods

Continued

Steps		Description	Duration
Read	1	With your partner, read or watch the resource you selected. Collect the following information to share with your group:	15 minutes
		For the article <i>What is Gene Therapy</i> ?	
		What is the treatment called?	
		What conditions help identify a patient that would benefit from gene therapy?	
		For the article <i>How Gene Therapy Works</i>	
		What are the different methods of gene therapy?	
		Why does each method help?	
		How does each method work?	
		For the article <i>Bone Marrow Transplant</i>	
		What is a bone marrow transplant?	
		What does bone marrow do for the body?	
		How does a bone marrow transplant help patients?	
	2	As you read, record the information in your Inherited Disease Treatments Mini-Session capture sheet.	
Share	1	Share the information with your group. Use the images in your resource to help teach other group members about your treatment.	12 minutes
	2	As group members share their information, take notes in your group share what they learned, record the information in your <i>Inherited Disease Treatments Mini-Session</i> capture sheet.	
Discuss	1	Based on what you have learned about each preventive treatment, discuss the following prompt: "What are the pros and cons for this type of treatment?"	5 minutes

#### **Inherited Disease Treatments Mini-Session, Part 1** *Preventive Treatments*

#### Directions

Use this capture sheet as you work through the mini-session with your group. This information will be used to develop the "Next Steps" section of your **Genetic Test Report**, so taking detailed and clear notes is vital.

Steps	Directions		
Think and Discuss	How is trying to treat an inherited disease similar and different from treating an illness like a flu or cold?		
Brainstorm	List your group's ideas on how people can avoid getting inherited diseases.		
Read and	Write your notes	Preventive	reatment: CRISPR
Share	from the <i>Read and Share</i> steps.	What is the	treatment called?
		How does it	work?
		Why does it	help prevent the inherited disease?

### Inherited Disease Treatments Mini-Session, Part 1

Preventive Treatments

Continued

Steps	Directions			
Read and Share	and       Write your notes       Preventive Treatment: Preimplantation Genetic Testing         from the Read and       What is the treatment called? (List all types of treatments.)         What is the treatment called?       How does it work?		penetic Testing pes of treatments.)	
		Why does it help prevent the inherited disease?		sease?
Discuss	List the pros and cons your group identifies for the preventive treatments.		Pros	Cons

**Inherited Disease Treatments Mini-Session, Part 2** *Reactive Treatments* 

#### Directions

Use this capture sheet as you work through the mini-session with your group. This information will be used to develop the "Next Steps" section of your **Genetic Test Report**, so taking detailed and clear notes is vital.

Steps	Directions	
Think and Discuss	How is trying to treat an inherited disease similar and different from treating an illness like a flu or cold?	
Brainstorm	List your group's ideas on the steps people can take when they are diagnosed with an inherited diseases.	
Read and Share	Write your notes from the <i>Read and</i> <i>Share</i> steps.	1       Reactive Treatment: What is Gene Therapy?         What is gene therapy?
		What conditions help identify a patient who would benefit from gene therapy?

### Inherited Disease Treatments Mini-Session, Part 2

Reactive Treatments

Continued

Steps	Directions						
Read and Share	Write your notes from the <i>Read and</i> <i>Share</i> steps.		Reactive Treatment: Methods of Gene Therapy Gene therapy method 1: Repairing mutations				
			Gene therapy method 2: Gene silencing				
			Gene therapy method 3: Genetically modifying immune cells to tar	get specific molecules			
Discuss	List the pros and cons your group identifies for the reactive treatments.		Pros	Cons			

### **Treatment Options for My Patient**

Preventive Treatment Option 1

#### Directions

Through the eyes of your role as a genetic counselor, use the Inherited Disease Treatments Online Resources to identify one or two preventative treatments you would recommend as options for your patient. This information will be used to create the "Next Steps" section of your Genetic Test Report.



Inherited Disease Treatments Online Resources

1.	What is the treatment called?	4.	Why does it help?
2.	Does it utilize CRISPR technology, Preimplantation genetic testing, or a different type of method?		
		5.	Why do you recommend it as an option for your patient over the other options you read about?
3.	How does it work?		
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### **Treatment Options for My Patient**

Preventive Treatment Option 2

#### Directions

Through the eyes of your role as a genetic counselor, use the Inherited Disease Treatments Online Resources to identify one or two preventative treatments you would recommend as options for your patient. This information will be used to create the "Next Steps" section of your Genetic Test Report.



Inherited Disease Treatments Online Resources

4. Why does it help?

2. Does it utilize CRISPR technology, Preimplantation genetic testing, or a different type of method?

3. How does it work?

5. Why do you recommend it as an option for your patient over the other options you read about?

### Treatment Options for My Patient

Reactive Treatment Option 1

#### Directions

Through the eyes of your role as a genetic counselor, use the Inherited Disease Treatments Online Resources to identify one or two reactive treatments you would recommend as options for your patients. This information will be used to create the "Next Steps" section of your **Genetic Test Report**.



Inherited Disease Treatments Online Resources

1.	What is the treatment called?	4.	Why does it help?
2.	What method of gene therapy does it utilize, or does the treatment use a different type of therapy?	_	
		_	
		5.	Why do you recommend it as an option for your patient over the other options you read about?
3.	How does it work?		
		_	

### Treatment Options for My Patient

Reactive Treatment Option 2

#### Directions

Through the eyes of your role as a genetic counselor, use the Inherited Disease Treatments Online Resources to identify one or two reactive treatments you would recommend as options for your patients. This information will be used to create the "Next Steps" section of your **Genetic Test Report**.



Inherited Disease Treatments Online Resources

1.	What is the treatment called?	4. V	Vhy does it help?
2.	What method of gene therapy does it utilize, or does the treatment use a different type of therapy?		
		5. V o	Vhy do you recommend it as an option for your patient ver the other options you read about?
3.	How does it work?		

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# FUTURELAB+

#### **Bioethics of My Work as a Genetics Counselor**

#### Directions

Follow the steps below to discuss the dilemmas you face as a genetic counselor and the dilemmas your patient faces when they receive your Genetic Test Report. This is a self-guided activity, so identify one person in your group to be the Facilitator and one person to be the Clock Keeper.

#### Roles

Facilitator Reads the directions for each step and leads the group through the procedure for each step. .....

*Clock Keeper* Keeps track of the time for each step. This person makes sure the group does not go under or over time for each step. 

Steps		Description	Duration	
Brainstorm	1	First, individually write down the diff counselor and anticipate what your p <b>Genetic Test Report</b> .	5 minutes	
	2	Then, share your examples as a group already on your list.		
	· · · · · · · · · · · · · · · · · · ·	Dilemmas I may face as a genetic counselor	Dilemmas my patient may face when they receive my <b>Genetic Test Report</b>	
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#### Bioethics of My Work as a Genetics Counselor

Continued

Steps		Description	Duration	
Think	1	<ul><li>Read the prompts below, then record your thoughts in the proper space.</li><li>a. What do you think is the biggest dilemma for each person?</li><li>b. Why did you choose this dilemma?</li></ul>		5 minutes
		My role as a genetic counselor communicating the Genetic Test Report to my patient	My patient receiving the information about the inherited disease in the Genetic Test Report	
		a.	a.	
		b.	b.	
Share	1	As a group, take turns sharing what	you think is the biggest dilemma faced by	5 minutes
		both perspectives.		
Discuss and Decide	1	Discuss the following prompts in your group. Record ideas as you discuss what came up in your group as you discussed each question.		5 minutes
		a. Should a genetic counselor tell their patient which treatment option they should choose?		3–4 minutes for each promt

### Bioethics of my work as a Genetic Counselor

Continued

Steps	Description	Duration
Discuss and Decide	b. How do genetic counselors ensure their personal bias does not interfere with their communication or treatment of their patients?	3-4 minutes for each prompt
	<b>c.</b> How do the ethical dilemmas impact how genetic counselors communicate with their patients?	
	d. How will these dilemmas impact how we create our Genetic Test Report for our patient?	

### **Close Reading Protocol Activity**

Adaptations and Gene Expression

#### Directions

- 1. Before reading this passage, write your current knowledge of what the key term means. This is based on your understanding of the word. If you do not know what it means as an everyday term, then make an educated guess.
- 2. You will read the article twice. As you read the first time, pay attention to the possible definitions and <u>underline</u> them (or key phrases).
- 3. After reading the article the first time, write the scientific definition of the term.
- 4. Discuss the information with a partner.
- 5. Read the article a second time and answer the two questions at the end of the article.

	Complete before reading	Complete after reading		
Key Term	Everyday Definition	Scientific Definition		
Anatomical or Structural Adaptation				
Behavioral Adaptation				
Physiological Adaptation				

#### **Close Reading Protocol Activity**

Adaptations and Gene Expression Continued

An adaptation is a characteristic that makes an organism more suited to its environment. It is any heritable trait that helps an organism, such as a plant or animal, survive and reproduce in its environment.

Adaptations that affect how an organism acts are called behavioral adaptations. Bears hibernate to escape cold seasons; birds and whales migrate to warmer winter climates; desert animals are active at night during hot summer weather. Humans even have cultural adaptations as a subset of behavioral adaptations. People who live in a given environment learn ways of raising the food they need and managing with the particular given climate.

An organism's environment shapes its appearance through structural adaptations. Desert foxes have large ears for heat radiation and Arctic foxes have small ears to retain body heat. Eagles and other birds of prey have sharp, hooked beaks that can tear into the flesh of their prey, while sparrows and other seed-eating birds have short, pointed beaks for cracking open seeds. Seals have flippers to navigate water and raccoons have separate, flexible digits to eat their food.

Physiological adaptation is an internal body process to regulate and maintain homeostasis. This process helps animals and plants ensure their survival in their environment or habitat. Gene expression can be influenced by the environment. This environment includes the world outside and inside an organism. The internal world may include factors such as metabolism or gender. External influences could be food, substances in the environment, light, and temperature. Some of these will influence which genes are switched on or off. This may alter how an organism functions and develops.

Food availability can influence gene expression. Certain gut bacteria produce specific enzymes only when certain types of food are present. The bacteria can alter the types of enzymes according to nutrients present in the food. Imagine that you had cereal and milk for breakfast. The bacteria produce enzymes specifically to digest carbohydrates and fats from this meal. Imagine that you then have a hamburger and salad for lunch. The bacteria now produce enzymes to digest fats and fiber. These bacteria produce different enzymes by turning on and off certain genes due to changes in the food substances in their environment. This helps the bacterium and its host.

Chemicals or drugs in the environment can change gene expression. One example involved a drug called thalidomide. Thalidomide was a drug that was used in the 1950 and 1960s to prevent nausea. In adults, it had no measurable effect on gene expression and was widely prescribed. However, it was later discovered to alter gene expression in fetuses. Many pregnant women who had been prescribed the drug gave birth to infants with missing or malformed arms and legs. About 10,000 infants were impacted in this way.

Temperature can alter gene expression. One example is the Himalayan rabbit. Himalayan rabbits carry a gene which is needed for pigment production. The expression of this gene depends upon the temperature. The rabbit is in cold conditions. All parts of its body are exposed to the cold. This makes it sound like the ears are cold but the tail, for example, is warm.

Light may also alter gene expression. For example, exposure of some caterpillar species to different colors of light will change the color of the wings they develop as butterflies. In a study, those exposed to green light had dark wings, whereas those raised under red light had very brightly colored wings.

There are many examples of the environment influencing gene expression. Genes that are influenced by internal and external environmental factors may provide certain adaptive advantages and will be selected for through the process of natural selection.

#### **Close Reading Protocol Activity**

Adaptations and Gene Expression Continued

- 1. Sometimes, variations occur in the process of gene expression. This can include erroneous substitution, insertion, or deletion of a nucleotide, which is called a gene mutation. Using one example from the text, describe how gene expression can provide an adaptive advantage.
- 2. Summarize the three types of adaptations by sketching an image that helps you remember each term.

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Anatomical	UI.	Structural	Aual	lation

#### Behavioral Adaptation

Physiological Adaptation