

FUTURELAB+

LIVING EARTH

*Genetic Detectives:
Investigating Inherited Diseases*

Unit 1 Living Earth

Design Journal

Developed in partnership with:

Discovery Education

FUTURELAB+

Unit 1 Living Earth

OBJECTIVES

Students will be able to:

Discover who is impacted by inherited diseases.

Investigate different types of genetic and inherited diseases.

Explore the role of a genetic counselor.

PROJECT SUMMARY

Genetic Test Report

Heritable Disease Posters

Flipgrid Presentation and Visuals

BACKGROUND

Genetic disorders have plagued mankind for millennia. What we have learned about the human genome, combined with scientific advances in medicine and research, has extended humans' life expectancy, prevented unnecessary suffering, and enabled patients to make informed decisions about genetic disorders.

Genetic diseases are caused by mutations in DNA. These mutations are the result of errors made during the transcription process. DNA mutations can be passed down to offspring, who may or may not display traits related to the mutation. These are known as inherited diseases. This lesson focuses on people who are born with inherited diseases and explores how the diseases impact their daily lives.

Throughout the unit, students explore the career of genetic counseling. Genetic counselors are health care professionals who help patients understand how to navigate the information contained in their genetic code. Students act as genetic counselors by developing a test report for a selected patient profile. As they develop and present their report, students must display many of the skills that genetic counselors use in their work. These include displaying empathy to patients, communicating complex information to individuals with low health literacy, analyzing genetic data and identifying a patient's best pathway for care.

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Proposal Requirements

The Genetic Test Report must include:

- 1 Description of the disease, including symptoms, risk factors, and populations impacted most by this disease.
- 2 Statistics that show the impact of the disease in the selected heritable disease nationally or globally.
- 3 Specific genetic information about the disease and what they indicate about a person's risk.
- 4 The ability to be easily understood by a person.

The Heritable Disease Posters must include:

- 1 What you learn about the people who get the genetic disease.
- 2 What you learn about the people who are indirectly affected by the genetic disease.
- 3 What you learn about the symptoms of the people who have the genetic disease.
- 4 What you learn about how someone gets the genetic disease.
- 5 How a genetic counselor tests someone to see if they have the genetic disease.

The Flipgrid and Visuals presentation must include:

- 1 Background information on the disease and statistics supporting why this is an important issue related to human health.
- 2 An explanation of how the genetic test data can provide clues about the disease and the risk factors involved or health decisions required from an individual or family.
- 3 An explanation of how the report would provide genetic risk data in a realistic way.
- 4 Information about how a person or physician would access data and use it to make health decisions.

Project Design Process Journal

Name

Team Members

Start Date

Due Date

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Project Design Process Journal

Step 1: Define the Problem	Step 2: Brainstorm	Step 3: Research and Generate Ideas	Step 4: Identify Criteria and Specify Constraints	Step 5: Explore Possibilities	Step 6: Select an Approach	Step 7: Develop the Design Proposal	Step 8: Make a Model or Prototype	Step 9: Test and Evaluate Design Using Specifications	Step 10: Refine the Design	Step 11: Modify and Present for Market	Step 12: Reflect
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Step 1: Defining the Problem

According to the Genetic Disease your team has chosen, what is the problem and/or the need that justifies the creation of these products/projects?

What evidence do you see of this problem and/or need when you think about what you have learned in the lessons for this unit?

What are the three requested products?

1. _____

2. _____

3. _____

Describe what needs to be communicated in each product?

1. _____

2. _____

3. _____

How can a proposed design project/products increase a person's ability to obtain information about their health and disease?

What are the constraints for these products?

What are the critical questions that need to be answered in order to be able to produce these products?

1. _____

2. _____

3. _____

What do you already know about these questions?

What resources will you use to find out more information about these questions?

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Step 2: Brainstorm

Discuss initial ideas with the whole team. In the space provided, create a concept map, flow chart, or other type of graphic organizer showing how you might connect information about inherited disease to the issues of health literacy, risk of and access to information about your chosen disease. What will the goal of each piece of the unit projects be? To inform and guide? A call to action? Remember to be creative!



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Step 3: Research and Generate Ideas

On the table below, think about possible questions you need to answer to gather more information prior to committing to one of your ideas. What resources are available to assist you in answering your questions?

Resource List

Possible Questions Generate a list of specific questions that need to be answered	Collected Information to Answer the Question	Any Additional Design Ideas Generated During Research Notes or sketches

Possible Question starters:

- What are specific populations at risk for this disease or human health issue?
What will the target audience be for the products?
- Have products like this been created previously? If so, what are the shortcomings of these that you would want to avoid?
- Is there a similar product where components could apply to these types of products?
- What type of platform should the product be created for? Is there information to help me choose the best platform for the product?
- What data resources might be helpful when creating my product?

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Project Design Process Journal

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Lesson Connections

LESSON 1: Inherited Diseases

Use the capture sheets and information learned from this lesson to answer the following questions:

What is the role of a genetic counselor?

What is an inherited disease?

Whose lives are impacted by inherited diseases?

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Project Design Process Journal

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Making Connections

What I learned from this lesson:

How this connects to the project:

Which part(s) of the project does this lesson address and how might it be used?

Genetic Test Report

Poster Design and Production

FlipGrid Video Presentation and Visuals

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Project Design Process Journal

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Lesson Connections

LESSON 2: Genetics

Use the capture sheets and information learned from this lesson to answer the following questions:

How do genes get passed from parents to offspring?

How do we conduct tests that inform us about the possibility of inherited disease?

How does this connect to the inherited diseases you learned about in lesson 1?

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Project Design Process Journal

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Lesson Connections

LESSON 3: Genetic Mutations

Use the capture sheets and information learned from this lesson to answer the following questions:

What is the genetic code?

How is the information in DNA used to make proteins?

How do mutations give rise to altered proteins?

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Project Design Process Journal

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Lesson Connections

LESSON 3: Genetic Mutations

Use the capture sheets and information learned from this lesson to answer the following questions:

How do the altered proteins developed from mutations in DNA give rise to specific inherited diseases?

How do you counsel a patient with low health literacy on their risk of genetic disease?

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Project Design Process Journal

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Making Connections

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How this connects to the project:

Which part(s) of the project does this lesson address and how might it be used?

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Lesson Connections

LESSON 4: Treating Inherited Disease

Use the capture sheets and information learned from this lesson to answer the following 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?

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Making Connections

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How this connects to the project:

Which part(s) of the project does this lesson address and how might it be used?

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Lesson Connections

LESSON 5: Communicating a Genetic Test Report

Use the capture sheets and information learned from this lesson to answer the following questions:

How do we communicate with patients who may have an inherited disease?

How does health literacy impact the delivery of the genetic test report?

How do factors like a patient's age, gender, culture, health literacy, or other factors impact how the genetic test report should be presented to their patient?

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Making Connections

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How this connects to the project:

Which part(s) of the project does this lesson address and how might it be used?

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Lesson Connections

LESSON 6: Genetic Counseling

Use the capture sheets and information learned from this lesson to answer the following questions:

How do we present our information clearly, concisely, and logically?

How do we ensure we include key information, develop ideas, and present in a manner appropriate for our purpose, task, and audience?

What are some of the benefits of transforming quantitative or technical information into effective visuals and vice versa?

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Making Connections

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How this connects to the project:

Which part(s) of the project does this lesson address and how might it be used?

Genetic Test Report

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Step 4: Identify Criteria and Specify Constraints

What are specific criteria and constraints for your chosen disease and patient profile? How do they affect each product you are creating?

Criteria

Genetic Test Report

Poster Design and Production

FlipGrid Video Presentation and Visuals

Constraint

Genetic Test Report

Poster Design and Production

FlipGrid Video Presentation and Visuals

Potential Materials Needed

Genetic Test Report

Poster Design and Production

FlipGrid Video Presentation and Visuals

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Project Design Process Journal

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Step 5: Explore Possibilities

Review your ideas from the Brainstorm and Research sections of your Design Journal. Explore some of your ideas with more detail. Record your exploration in the space below. Possible explorations can reflect testing, experiments, simulations, peer review, etc. Be sure to include any data collected or group discussion and feedback. Do this for each product.

Genetic Test Report

Poster Design and Production

FlipGrid Video Presentation and Visuals

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Project Design Process Journal

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FlipGrid Video Presentation and Visuals

Criteria or Constraint	Sketch/Idea 1	Sketch/Idea 2	Sketch/Idea 3

Other criteria: A single rating for your own “nice-to-have,” desirable criteria and universal design criteria (such as *Robustness, Aesthetics, Cost and Resources, Time, Skill Required, Safety*):

Totals _____

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Step 8: Document Design Creation

In the space below, document (using digital pictures) your design and creation of the Heritable Disease Poster and Flipgrid Presentation. Be sure to include a picture of the final product.

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Step 9: Evaluate the Design

How will you obtain feedback about your designs?

What data will you collect during evaluation?

In the space below, document the type of evaluation you conducted and the results for each product you created.

Genetic Test Report

Description of Evaluation Questions

Evaluation Results

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Poster Design and Production

Description of Evaluation Questions

Evaluation Results

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

FlipGrid Video Presentation and Visuals

Description of Evaluation Questions

Evaluation Results

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

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Step 11: Modify and Present

What changes (if any) did you make to your designs after feedback in the Evaluate the Design step of this project?

All products and presentations must include:

- 1 Background information related to the disease and how such things as genetic test reports, information about heritable diseases, and your Flipgrid Presentation and Visuals can help people make appropriate health decisions.
- 2 Features that are targeted to your specific audience. (For example, if your target audience is non-english speaking, it may be helpful to add subtitles in that language or record a second video with a voiceover in the native language of that group.)

The Genetic Report project must include:

- 1 Description of the disease, including symptoms, risk factors, and populations impacted most by this disease.
- 2 Statistics that show the impact of the disease in the selected heritable disease nationally or globally.
- 3 Specific genetic information about the disease and what they indicate about a person's risk.
- 4 The ability to be easily understood by a person.

The Heritable Disease Posters must include:

- 1 What you learn about the people who get the genetic disease.
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The Flipgrid and Visuals presentation must include:

- 1 Background information on the disease and statistics supporting why this is an important issue related to human health.
- 2 An explanation of how the genetic test data can provide clues about the disease and the risk factors involved or health decisions required from an individual or family.
- 3 An explanation of how the report would provide genetic risk data in a realistic way.
- 4 Information about how a person or physician would access data and use it to make health decisions.

Consider how a Genetic Counselor in today's workforce would deliver a genetic test report or real world presentation. Use the space below to explain what further work might need to be done in order to prepare this product or presentation to an at-risk audience.

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Step 12: Reflection on Process

Answer the following questions about your products.

What were the best things about your project process?

What were some weaknesses of your project's design?