December 2025

Gene-ius at Work: Genetic Counseling and Cystic Fibrosis

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ABE Master Teacher Fellowship Program

AMGEN Biotech Experience

Scientific Discovery for the Classroom

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We are grateful to the ABE Master Teacher Fellows for sharing their work with the ABE community. If you have questions about any of the project components, please reach out to us at ABEInfo@edc.org, and we will be happy to connect you with the author and provide any assistance needed.

AMGEN Biotech Experience

Scientific Discovery for the Classroom

Australia

Gene-ius at Work: Genetic Counseling and Cystic Fibrosis

Gene-ius at Work: Genetic Counseling and Cystic Fibrosis

TIME FRAME:	Approximately 10 hours
TARGET STUDENTS:	This resource is intended to be used by students in Year 10 completing a unit called "Genetics and Evolutionary Change." This unit forms part of the final year of compulsory Science education in NSW, Australia.
SYLLABUS CONTENT:	Genetics and Evolutionary Change: • Outline the connection between genotypes and phenotypes, using Mendelian inheritance for both plants and animals • Use pedigrees and Punnett squares to model monogenic gene-trait relationships and make predictions about patterns of inheritance • Identify examples of current and emerging genetic technologies • Discuss applications of genetic technologies in conservation, agriculture, industry and medicine • Discuss the applications of genetic testing and its associated social, economic and ethical implications Working Scientifically: • Assemble, construct and manipulate identified equipment to perform the investigation • Follow the planned procedure and identify and respond to errors if they occur • Select and use a range of representations to organise data and information, including graphs, keys, models, diagrams, tables and spreadsheets • Use knowledge of scientific concepts to draw conclusions that are consistent with evidence • Present scientific arguments using evidence, correct scientific language and terminology, as appropriate to audience and purpose • Create written texts to communicate scientific investigations, explain scientific theories and principles, structure a scientific argument, and evaluate findings in light of scientific knowledge[1]
SUMMARY OF LESSON SEQUENCE:	Students will adopt the role of a genetic counselor to present information to parents who are seeking to have a third child. The mother is concerned that a future child may have cystic fibrosis, as both her brother and his daughter have the disease. Students will construct a pedigree chart of the family and identify the genotypes of individuals based on the phenotypic information given and patterns of inheritance. Then, students will identify individuals for genetic testing to determine the probability of the mother and father having a future child with cystic fibrosis, and the genotype of their previous children. Students will then choose which of the following tasks they would like to complete: • Prepare a genetic screening report for the parents, explaining information about cystic fibrosis, the tests conducted, analysis of results, and implications for each of the individuals tested (individual task).

[1]NESA. (2025). *Science 7-10 Syllabus*. https://curriculum.nsw.edu.au/learning-areas/science/science-7-10-2023/overview

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	• Write a script for an interview between the parents and genetic counselor explaining the results of the tests conducted, and the implications for each of the individuals tested. Students will film the interview (group task). Students will then engage in research to write a discussion essay exploring the social and ethical implications of genetic testing. Students will use a scaffold and suggested sources to explore implications of genetic testing.
ASSESSMENT:	There are opportunities for both formative and summative assessment in this lesson sequence. These include: • Questioning and observation during classroom activities • Written responses, including pedigrees and Punnet squares • Genetic screening report or filmed discussion between genetic counselor and parents • Discussion essay exploring implications of genetic testing

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Overview of Lesson Sequence

Lesson 1: Cystic Fibrosis

- The teacher shares the scenario with students, and outlines assessment requirements (if any).
- Students research the causes, symptoms, and treatment of cystic fibrosis.

Lesson 2: Inheritance Patterns

- Students construct a pedigree from the given scenario data and identify individuals with cystic fibrosis. Annotate the pedigree with the known genotypes of individuals.
- Students identify individuals to be tested and justify these decisions using a claim-evidence-reasoning scaffold.

Lesson 3: Using a Micropipette

- Students learn how to use a micropipette and load a gel for gel electrophoresis using ABE Lab 1.1.

Lesson 4: Gel Electrophoresis

- Students run a gel to determine the genotype of selected individuals, following ABE Lab 1.2B with some modifications. NOTE: Dye mixtures will be used in place of DNA samples during electrophoresis.

Lesson 5: Interpreting and Communicating the Results

- Students examine the results obtained from gel electrophoresis and analyse these in the context of the scenario.
- Students determine the probability of two potential parents having a child with cystic fibrosis.
- Students, in the role of genetic counselors, communicate the results of the genetic testing to the potential parents.

Lesson 6: Ethics of Pre-implantation Genetic Testing

- Students learn about pre-implantation genetic testing and participate in a class discussion about the ethical implications of the use of this biotechnology.
- Students write an essay discussing the ethical implications of the use of pre-implantation genetic testing.

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Lesson 1: Cystic Fibrosis

Learning intention:

We are learning about the causes, symptoms and treatment of a genetic disease.

- I can use reliable secondary sources to find information about a genetic disease.
- I can describe the causes, symptoms and treatment of a genetic disease using appropriate terminology.
- I can explain how a genetic mutation impacts the phenotype of individuals.

Outline:

The teacher will introduce the scenario to students, who will begin background research into cystic fibrosis. Teacher will model the use of the CRAAP test, which students will apply to select appropriate secondary sources. Then, students will complete a scaffold to demonstrate understanding of the impact of a genetic mutation that causes cystic fibrosis on phenotype.

Sequence of Activities:

Activity	Description	Time	Resources
1	Students read and discuss the scenario. Teacher explains unfamiliar terminology if required. Discuss what questions students need answers to before they step into the role of genetic counselors.	15 min	Worksheet: Task and Scenario
2	Students research the cause, symptoms and treatment options for cystic fibrosis. The teacher explains and/or models the use of the CRAAP test[2] to determine the reliability of a source of information.	25 min	Worksheet: CRAAP Test Devices for research
3	Students complete the table comparing the effect of a wild type and mutated allele at the DNA, protein, cellular, tissue, system and organism levels.	20 min	Worksheet: Linking Genotype to Phenotype

Differentiation:

- Students could be provided with sources of information for their research activity, such as: Cystic Fibrosis Australia, Cystic Fibrosis (Better Health Channel), Cystic Fibrosis (Health Direct).
- Provide guiding questions to help students research the cause, symptoms and treatment options for cystic fibrosis.
- Model the use of the CRAAP test with another website for an alternative genetic disease.
- Provide sentences for students to use to complete the table comparing the function of the wild type and mutant alleles.
- Display an example scaffold for another genetic disease, demonstrating how genotype and phenotype are linked.

[2] Blakeslee, S. (2004). "The CRAAP Test," *LOEX Quarterly*: Vol. 31: No. 3, Article 4. Available at https://commons.emich.edu/loexquarterly/vol31/iss3/4

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Assessment:

Completed research and worksheets can be used to check student understanding.

Task and Scenario

Task:

For this task, you will become a genetic counselor. Genetic counselors are health professionals that provide personalised genetic information to patients with, or at risk of, genetic diseases. You can read more about genetic counselors at A career as a genetic counselor (NSW Health).

During this task, you will:

- examine the inheritance of a genetic condition within a family.
- select and test individuals from this family to determine the genotype of individuals.
- provide genetic information to a patient and make recommendations about the risk of passing the condition on to future children.
- discuss the ethics of using pre-implantation genetic testing to prevent inheritance of a genetic disease.

Scenario:

A potential mother and father have approached you for advice. The mother is concerned that a future child may have cystic fibrosis, as she has an older brother who has cystic fibrosis. His cystic fibrosis is caused by two copies of the F508del allele. He has three children with his partner: two boys without the disease and a daughter with cystic fibrosis. Neither of the potential mother's parents have the disease. The mother has a younger sister with two boys with her partner, none of whom have cystic fibrosis.

In the potential father's family, there is one cousin who has undergone genetic testing and is a carrier for cystic fibrosis.

The potential parents would like to know the chance that any future children would have cystic fibrosis, and what their options are if there is a chance that the future child would have the disease.

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CRAAP Test

Use the following scaffold[3] to assess the reliability of a source you have used to access information about cystic fibrosis. For each section, think about the questions, write some notes in the space provided, and give the source a score out of 5, where 1 indicates a bad source and 5 indicates an excellent source. If the information to answer a question isn't available, give it a low score. There are no rules about interpreting these scores, but if you have given a source low scores across multiple categories, you should avoid relying on the source.

Criteria	Comments	Score
Currency: Is the information timely? What was the publication date? When was the information written or posted? Is it up to date? If there are links, are they functional? Has the information been updated?		/ 5
Relevancy: Is the information relevant to the topic? Does the information help you answer your question? Does it tell you what you need to know? Is the information at the right level for you? Is the information too basic? Is the information too advanced? What country is it from?		/ 5
Authority: Are the authors or publishers credible? Who is the author? What are their credentials? Are they qualified to write about this topic? What else have they written about? If an organisation, what is the nature of the organisation? Can you tell who owns or operates the organisation? What can you tell from the URL (.com, .com.au, .edu., .org, .gov., .net)? Is there contact information? Is the layout professional?		/ 5

[3] Modified from AERO. (2024). "Evaluating non-academic sources" *Australian Education Research Organisation*. Available at: https://www.edresearch.edu.au/guides-resources/practice-resources/evaluating-non-academic-sources-craap-test

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Criteria	Comments	Score
Accuracy: is the information likely to be correct? Is there evidence to support the information provided? Are references referenced? Are they current and academic sources? Can you verify the information elsewhere? Is the language objective? Are there signs of political, personal or other biases? Is it well-written, with no spelling or grammatical errors?		/ 5
Purpose: is the information likely to be biased? Is the purpose (inform, entertain, persuade, sell) of the information made clear? Who is the intended audience? Is it promoting a service or product? Is it likely the author or organisation has an agenda?		/ 5

Overall judgement about the reliability of the source and justification:

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Linking Genotype to Phenotype

Complete the table to show the connection between genotype for individuals with the wild type allele and the F508del allele.

Wild-type allele	Level	F508del allele
	DNA	
	Protein	
	Cell	
	Tissue	
	System	
	Organism	

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Linking Genotype to Phenotype: Sickle Cell Example

HBB	Level	HbS
CTC at position 6 of the gene for the β-globin chain	DNA	Single nucleotide mutation: CAC at position 6 of the gene for the β-globin chain
Position 6 has glutamate, with normal folding of the β-globin chain, forming HbA molecules Transport oxygen normally	Protein	Position 6 has valine, with abnormal folding of the β-globin chain, forming HbS molecules In low oxygen environments, HbS molecules from
Red blood cells have a doughnut-like shape	Cell	Red blood cells have a sickle shape and are less flexible
Red blood cells survive for about 100–120 days in the body	Tissue	Sickle cells only last 10–20 days, requiring replacement to maintain oxygen transportation
Circulatory system efficiently transports oxygen around the body, with haemoglobin bonding to oxygen	System	Circulatory system: less effective at transporting oxygen around the body, sickle cells can cause blockages
Normal functioning of organism	Organism	Pain, anaemia, swelling, increased risk of bacterial infections, increased risk of stroke due to blockages Reduced life expectancy

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Lesson 2: Inheritance Patterns

Learning intention:

We are processing information about the inheritance of a genetic disease within a family.

- I can draw a pedigree for a scenario.
- I can use Punnett squares to determine the possible genotype(s) of individuals.
- I can use evidence and reasoning to support claims.

Outline:

The teacher will review with students conventions for drawing pedigrees and Punnett squares. Students will then use the scenario to draw a pedigree for the family, and then use Punnett squares to determine genotypes of individuals within the family. In small groups, students will then select individuals for genetic testing and provide an argument supporting their decisions.

Sequence of Activities:

Activity	Description	Time	Resources
1	Review conventions for drawing pedigrees and Punnett squares.	10 min	Data Book: Science 7-10[4]
2	Students draw a pedigree depicting the family described in the Scenario (see Lesson 1). Use appropriate conventions to identify the individuals, and where possible determine genotypes using Punnett squares.	25 min	Worksheet: Task and Scenario
3	Students use a claim-evidence-reason scaffold to build evidence-based arguments to test particular individuals.	25 min	Worksheet: Claim-Evidence-Reason scaffold

Differentiation:

- Provide a pedigree for students that show the correct familial relationships but not which individuals have the condition.
- Provide an example completed claim-evidence-reason scaffold for an alternative scenario to illustrate the key features of an evidence-based argument. The first row could be used to model the process.
- Use questions to encourage students to think about which individuals to test, for example: How will we know an individual has the F508del allele without anything to compare a screening test to?

Assessment:

Check for student understanding by asking questions such as: What is the probability of the mother being a carrier of cystic fibrosis? Why do we know her older brother's genotype but not her younger sister's? How will you know a carrier has the F508del allele, and not a harmless mutation?

The pedigree and Punnett squares provide an opportunity to check student understanding of these scientific representations.

[4] NESA. (2023). *Science 7-10 (2023) Data Book*. Available at https://curriculum.nsw.edu.au/file/f1afc7c5-1f6d-4f07-9d87-dbdbb3eca83b/science-7-10-2023-data-book.pdf

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The claim-evidence-reason scaffold provides insight into student understanding of the scenario, the role of genetic counseling, and the capacity to make evidence-based claims.

Claim-Evidence-Reasoning

Determine which individual(s) you will conduct genetic testing on and why. Use the claim-evidence-reasoning scaffold below to justify your decisions.

Claim: an answer to the question or response to a prompt	**Evidence:** identify relevant information from experiments, stimulus material, or secondary sources	**Reasoning:** explain how the evidence supports the claims by linking the two together
State the claim using key terminology such as allele, carrier, or genotype.	Provide evidence to support the claim, including Punnett squares, and/or calculated probabilities of an individual being a carrier.	Link the evidence and claim together.
Individual …….. should be tested.		As individual …….. has a ……..% probability of being a carrier, they should be tested to determine if they are, in order to calculate the probability of their offspring having cystic fibrosis.

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Lesson 3: Using a Micropipette

Learning intention:

We are learning about common equipment and techniques used in biotechnology.

- I can use a micropipette to dispense accurate amounts of a liquid.
- I can describe how gel electrophoresis can be used to separate strands of DNA.
- I can load a gel for gel electrophoresis.

Outline:

The teacher will introduce the technique of gel electrophoresis. Students will then practice using a micropipette in preparation for running a gel next lesson. This lesson follows ABE's Laboratory 1.1 and Laboratory 1.2A.

Sequence of Activities:

Activity	Description	Time	Resources
1	Explain how gel electrophoresis can be used to determine if an individual has the longer wild type allele or the shorter F508del allele.	20 min	
2	Demonstrate how to use a micropipette. Students will need to be able to use a P20 micropipette in the next lesson.	20 min	Micropipettes Loading dye Laminated sheets
3	Demonstrate how to load a gel using a micropipette. Students can then practise loading a gel with the practice plates.	20 min	Micropipettes Loading dye Practice plates

Differentiation:

- Use a video (such as What is gel electrophoresis? (miniPCR bio) (7:30 min) to assist explaining gel electrophoresis to students.
- LabXchange can be used to prepare students for this laboratory, including using a micropipette and gel electrophoresis.
- Students may require additional time to practice using a micropipette. The times listed are optimistic.

Assessment:

Use the laminated cards and practice plates to check the development of student skills.

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Lesson 4: Gel Electrophoresis

Learning intention:

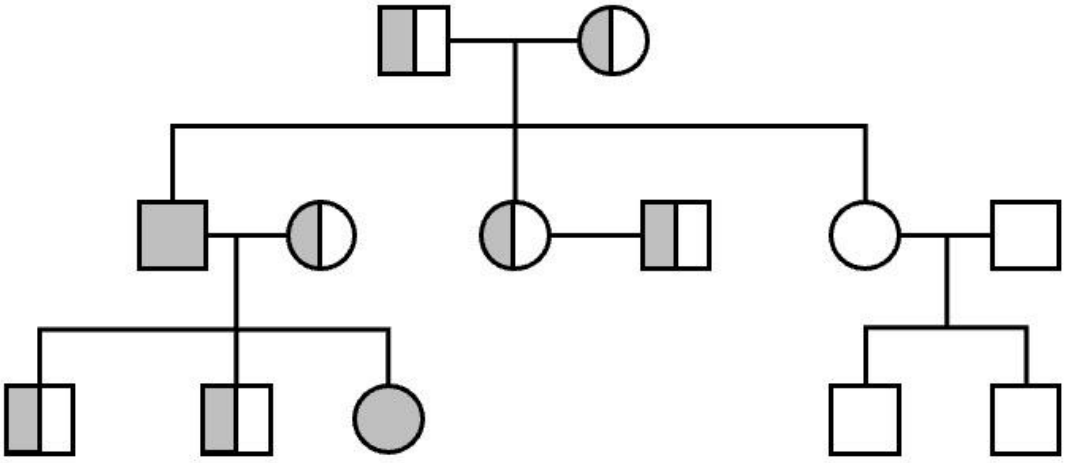
We are preparing and running gels to determine the genotypes of identified individuals.

- I can describe how gel electrophoresis can be used to separate strands of DNA.
- I can load a gel for gel electrophoresis.
- I can make predictions of expected results based on three different genotypes.
- I can record the results by drawing the relative location of bands.

Outline:

Students will make predictions about expected results of gel electrophoresis if individuals are homozygous for the wild type allele, heterozygous, or homozygous for the F508del allele. Then, students will prepare and run a gel to determine the genotype of selected individuals.

Teacher note: see the pedigree below to determine the genotype of individuals. Individuals who are homozygous for the wild type allele (no CF, not carriers) require a sample of xylene cyanole (S3 from Lab 1.2). Individuals who are heterozygous (no CF, carriers) require a sample of bromophenol blue and xylene cyanole (S1 from Lab 1.2). Individuals who are homozygous for the F508del allele require a sample of bromophenol blue. These should be prepared and in labelled microcentrifuge tubes with the individual's identity based on the pedigree constructed for each group in Lesson 2.



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Sequence of Activities:

Activity	Description	Time	Resources
1	Review the use of gel electrophoresis and make predictions if individuals are homozygous dominant, heterozygous (carrier of cystic fibrosis) or homozygous recessive (have cystic fibrosis).	15 min	Worksheet: Prediction and Results
2	Students prepare and run gels with dyes to determine the genotype of the individuals they identified in Lesson 2.	30 min	Equipment and reagents for Lab 1.2B Dyes
3	Students record results and clean up. Students can begin to examine their results and discuss what is indicated.	15 min	Worksheet: Prediction and Results

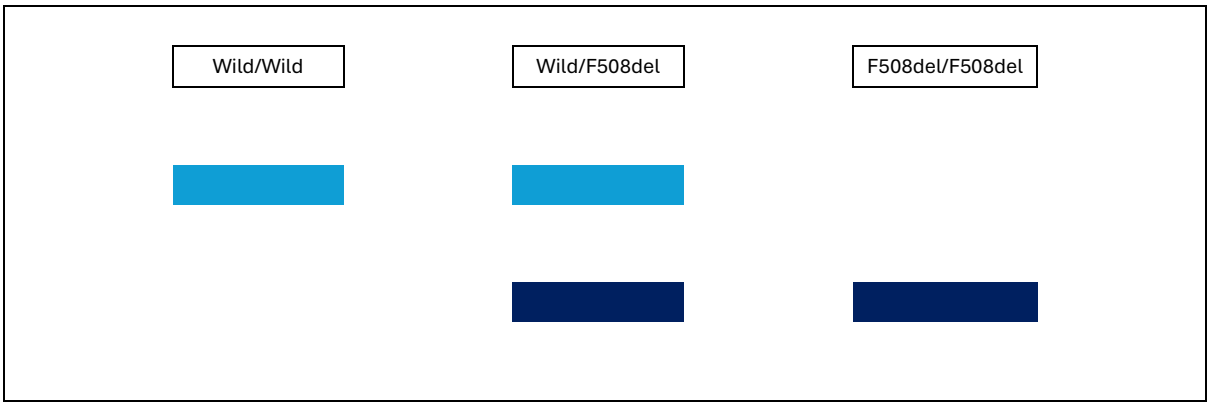
Differentiation:

LabXchange can be used to prepare students for this laboratory, including using a micropipette and gel electrophoresis.

Assessment:

Student predictions and results from the gel.

Prediction



- Individuals that are homozygous for the wild type should receive xylene cyanole (blue band on prediction)
- Individuals that are heterozygous should receive a mixture of xylene cyanole and bromophenol blue
- Individuals that are homozygous for the F508del allele (and have CF) should receive bromophenol blue (purple band on prediction)

The teacher will need to mix dyes and aliquot appropriately.

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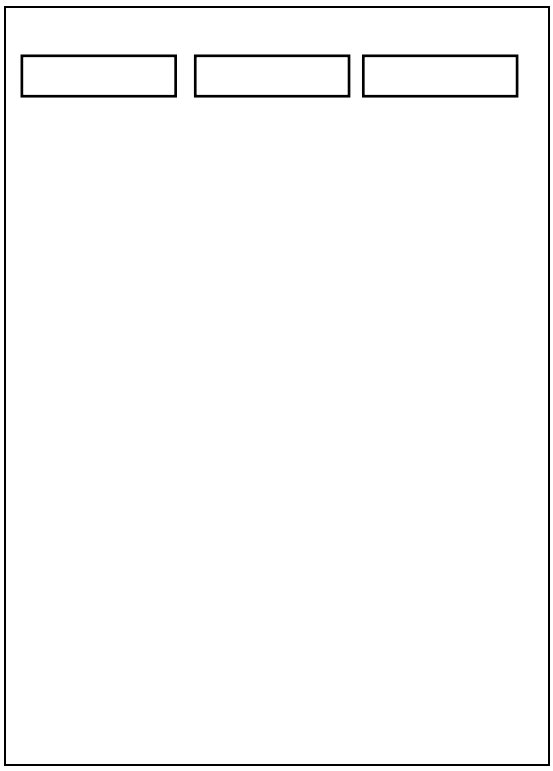
Prediction and Results

In the space below, indicate what is expected to be seen for the following genotypes:

- An individual homozygous for the dominant wild type allele at the *CFTR* gene.
- An individual heterozygous at the *CFTR* gene.
- An individual homozygous for the recessive F508del allele at the *CFTR* gene.



Record your results in the space below. Ensure you label which individual's DNA was tested in each well.

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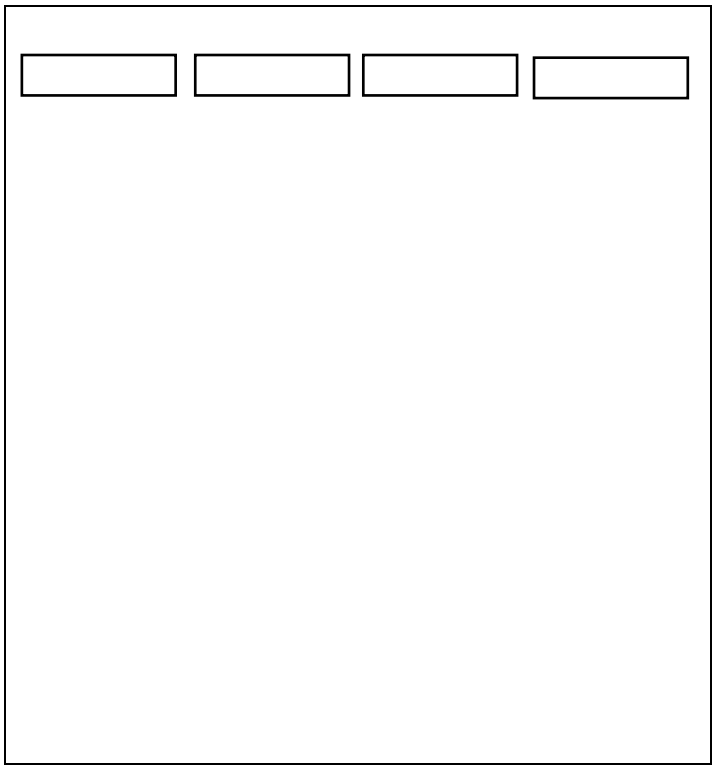

Lesson 5: Interpreting and Communicating the Results

Learning intention:

We are learning to interpret the results of gel electrophoresis.
- I can analyse the results of gel electrophoresis to determine the genotype of individuals.
- I can use genotypes to determine the probability of offspring having a genetic disease.

We are learning to communicate scientific information to a range of audiences.
- I can explain scientific concepts for a particular audience.
- I can use scientific terminology to convey key ideas.

Outline:

Students discuss their results and determine implications for the potential parents. Then, the teacher introduces how they will present their results to the potential parents: either through a genetic counseling report or a scripted interview session with the parents.

Sequence of Activities:

Activity	Description	Time	Resources
1	Class discussion about the results obtained from the gel electrophoresis. Students consider the implications for the parents.	20 min	
2	Introduce the task and brainstorm key considerations for presenting information to the potential parents. Consider both the scientific and emotional aspects of this communication. The “for	10 min	Worksheet: Genetic counseling scaffold

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	more information" section can be used to acknowledge sources of information.		
3	Students work on their projects to communicate their findings to the parents.	30 min	

Differentiation:

- Students may require additional time depending on the assessment product chosen.
- Provide students with an example of a genetic counseling report and a scaffold.

Assessment:

Students communicate the results as genetic counselors to the parents through either a genetic counseling report or a filmed interview session with the parents.

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Genetic Counseling Scaffold

GENETIC TEST REPORT

Patient details: **Test ordered by:** **Test carried out by:**

Reason for test:

Result:

About the test:

What this result means for you:

For more information:

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Genetic Counseling Scaffold: Phenylketonuria Example

GENETIC TEST REPORT

Patient details:
Ms. A. Person
1 Main Street
Town NSW 2000

Test ordered by:
Dr. M. Doctor

Test carried out by:
School Labs

Reason for test:	Family history of phenylketonuria. Patient intends to have a child.
Result:	Carrier of PKU alleles
About the test:	This test looked at the *PAH* gene on chromosome 12. This gene codes for an enzyme that breaks down phenylalanine, an amino acid. Variations of this gene can cause phenylketonuria (PKU). If you have a variation in **both** copies of the *PAH* gene you will have PKU. If you have a variation in **one** copy of the *PAH* gene you are a carrier. Carriers do not have PKU, but may pass on the variation to any children.
What this result means for you:	The test found that you have one variation of the *PAH* gene. You are a carrier for PKU. If you have children with someone who is also a carrier, there is a 25% chance each child you have will have PKU. There is a 50% chance that each child will be a carrier. There will be a 25% chance that each child will not receive the variation from either parent. If you have children with someone who has PKU, there will be a 50% chance that each child will have PKU. There will be a 50% chance that each child will be a carrier.
For more information:	Health Direct (2024) “Phenylketonuria." *Health Direct*. Available at https://www.healthdirect.gov.au/phenylketonuria

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Lesson 6: Ethics of Pre-implantation Genetic Testing

Learning Intention:

We are discussing the ethical implications of genetic technologies.
- I can describe how pre-implantation genetic testing can be used to prevent genetic diseases.
- I can use an ethical framework to discuss implications of the use of pre-implantation genetic testing.

We are learning to communicate scientific information to a range of audiences.
- I can explain scientific concepts for a particular audience.
- I can use scientific terminology to convey key ideas.

Outline:

Students are presented with information about pre-implantation genetic testing and discuss the possibility of using it when two parents are carriers of a genetic disease like cystic fibrosis. The teacher leads a discussion about the ethics of pre-implantation genetic testing, using a bioethical framework. Students then write an essay discussing the ethics of using pre-implantation genetic testing.

Sequence of Activities:

Activity	Description	Time	Resources
1	Identify that one possibility for the parents is pre-implantation genetic testing to reduce the chance of having a child with cystic fibrosis. Provide information about the processes involved in pre-implantation genetic testing.	20 min	
2	Lead a class discussion examining the issue of pre-implantation genetic testing using a bioethical framework.[5] Students can discuss aspects using a think-pair-share.	20 min	
3	Examine the scaffold and example essay.	20 min	Worksheet: Scaffold
4	Students write an essay discussing the ethical implications of pre-implantation genetic testing.	1 hour	

Differentiation:

- Provide students with a checklist of key parts that are expected in the final written essay.
- Students may require a scaffold or an example paragraph/essay. An example is included that discusses bioethical principles.
- Students could be encouraged to make notes during the class discussion to assist discussing the topic in a written format.

Assessment:

[5] See for example Beauchamp, T.L. and Childress, J.F. (2019). *Principles of Biomedical Ethics*. Oxford University Press: USA.

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Completed essays discussing the ethics of pre-implantation genetic testing.

Essay Scaffold

Introduction: **Introduce the topic, provide background information, and state the essay's purpose.** *What is pre-implantation genetic testing? How does pre-implantation testing work? What ethical principles will you discuss?*	
Body: **Focus on a specific aspect, issue, or viewpoint.** *Does the process of pre-implantation genetic testing demonstrate respect for autonomy? Can individuals provide informed consent? Are the rights of others protected?*	
Body: **Focus on a specific aspect, issue, or viewpoint.** *Does the process of pre-implantation genetic testing improve wellbeing? What are the benefits and risks? How reliable is pre-implantation genetic testing?*	
Body: **Focus on a specific aspect, issue, or viewpoint.** *Will privacy for individuals who use pre-implantation genetic screening be maintained? Will genetic information remain private?*	
Body: **Focus on a specific aspect, issue, or viewpoint.** *Will access to pre-implantation genetic screening be fair? Will everyone be able to access the procedure?*	
Conclusion: **Summarise the main points discussed and potentially offer a concluding opinion.**	

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Discussion Essay Example: Gene Therapy

Gene therapy is an innovative medical approach that involves altering the genes inside a person's cells to treat or prevent disease. By correcting defective genes responsible for disease development, gene therapy holds the promise of addressing genetic disorders like cystic fibrosis at their root cause. This essay aims to explore the ethical principles surrounding gene therapy, focusing on respect for autonomy, wellbeing, privacy, and equitable access. As advancements in genetic engineering continue to emerge, understanding the implications of gene therapy on individuals and society becomes increasingly vital.

The principle of respect for autonomy emphasises the importance of informed consent. In the context of gene therapy, patients must have the capacity to make decisions about their treatment options. This includes understanding the potential risks, benefits, and uncertainties associated with gene therapy. While many individuals may be eager to pursue gene therapy, the complexity of genetic information can pose challenges for informed decision-making. Furthermore, the rights of others, particularly in scenarios where gene therapy may impact future generations, must be considered. For example, should parents have the authority to make genetic decisions for their children, potentially infringing on the child's autonomy?

Gene therapy presents the potential to significantly improve the wellbeing of patients suffering from genetic disorders. By targeting the underlying genetic causes, gene therapy can offer long-lasting solutions, enhancing the quality of life for individuals and their families. However, there are risks involved. Adverse reactions, unintended genetic changes, and the long-term effects of therapy are critical factors to consider. The reliability of gene therapy also remains a subject of ongoing research. While clinical trials have shown promising results, the variability in outcomes and the need for rigorous testing highlight the importance of weighing the benefits against the potential risks.

Privacy is a significant concern in the realm of gene therapy, particularly regarding the handling of sensitive genetic information. Individuals undergoing gene therapy are often required to share personal genetic data, which raises questions about data security and confidentiality. Ensuring that this information remains private is essential. Additionally, the potential for genetic discrimination by employers or insurers presents another ethical challenge. Some employers or insurers may discriminate against individuals with a genetic disorder. As gene therapy becomes more prevalent, protecting individuals' privacy and preventing misuse of genetic information are essential.

The principle of justice in healthcare calls for fair access to medical treatments, including gene therapy. However, disparities in access based on socioeconomic status, geographic location, and healthcare infrastructure may hinder equitable distribution of gene therapy. While the technology holds immense potential, if only a select few can afford these cutting-edge treatments, the benefits may not be realised by all segments of society. Addressing these inequities is crucial to ensure that advancements in gene therapy are accessible to everyone, regardless of their background or circumstances.

In summary, gene therapy presents significant opportunities for treating genetic disorders, but it also raises complex ethical considerations. Respect for autonomy, the impact on wellbeing, privacy concerns, and equitable access are essential principles that must be carefully navigated as the field progresses. It is imperative to ensure that we act ethically and carefully consider the rights of individuals before using biotechnologies like gene therapy.

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