# Part 5
# Making Decisions

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*Narrator: It had been a week since Jenny got her test results. She'd waited for Jeremy to call to tell her about his results. But he hadn't called. Finally she couldn't stand the suspense any longer, so she picked up the phone and called him.*

Jeremy: Hi Jen, glad you called. When are you coming out here to visit me? The skiing here in Colorado is fantastic! I can get free lift tickets for you. That's one of the benefits of this ski instructor's job

Jenny: Jeremy, I know. I <u>will</u> make plans to visit you one of these days, but you know I didn't call you about skiing. I want to know what happened with your HD testing. It seems like I am more uptight about it than you are.

Jeremy: Well, if you really want to know, my doctor told me that I do have the gene. He was so serious about the whole thing, but I told him I'm not going to worry about it right now.

Jenny: I am so sorry, Jeremy. No wonder you didn't call. I can't believe you're taking the news so well. Now I wish I'd made those plane reservations so I could be out there with you.

Jeremy: Don't get all freaked out on me now, Jen. It's not the worst thing that could happen. I've always been good at taking what comes along, so I'll just focus on appreciating life more—you know, having fun. Any way, all this skiing is good for me—keeps me fit and active.

Jenny: But aren't you worried? I would be hysterical.

Jeremy: I can't worry about what might happen in 10 or 20 or 30 years. By then scientists will probably have a cure for HD. Stem cell therapy, gene therapy, medicines……I know they are working on finding a treatment or a cure.

Jenny: Have you contacted the Huntington's disease support group in your area?

Jeremy: Nope, I haven't had time. Oh, by the way, I haven't told Mom yet either. She left five messages on my answering machine asking about my test results. I am just waiting for a day in my schedule when I can be on the phone with her for a few hours before I call her. Hey, maybe <u>you</u> can tell her for me."

Jenny: Uh, uh! No way Jeremy! You know I'd do almost anything for you, but <u>not that</u>. You better make time to call her. I know she's really worried. She keeps asking Dad and me about your test results, and I don't want to be the one to break the news.

Jeremy: OK, okay, I get your point. I'll call her soon. By the way, how is Dad doing?

Jenny: He seems to have some good days and then some bad days. He's happy that he still has his job, at least for now. But the last time I saw him he started complaining about how difficult living alone and caring for himself has become.

Jeremy: Hey, that doesn't sound too good. When you talk to him, tell him that I'm thinking about him. Look Jen, I gotta go."

Jenny: Hey Jeremy! Wait! Are you still serious with your girlfriend, Liz? Have you told her that you have the HD gene?

Jeremy: Uh…. No and I really haven't figured out how to tell her. I know that Liz loves kids and I'm not sure how she'll react to all of this. I don't know if she'll want to stick around if she finds out.

Jenny: Yeah, I guess that's something you need to think about. Hey Jeremy, you know it seems that we focused so much on deciding whether or not to get tested that we didn't realize that getting the test results would just lead to more decisions.

*Narrator: Imagine what ethical, legal, and social implications the members of the Lanahan family will face in the future. What might be the new, major decisions that Jenny, Jeremy, their father, their mother, and their family and friends will have to make?*

Potential Ethical, Legal, and Social Implications for the Lanahans and Others

Name:_____ Class:_____

**What does your team think might be a major ethical, legal, or social implication that Jenny, Jeremy, their father, their mother, or family and friends might have in the future?**

**Jenny?**

**Jeremy?**

**Their father?**

**Their mother?**

**Their family and friends?**

Name_____ Members of your team _____

## #1: PROBLEM SOLVING RUBRIC

| Student: | 1<br>Limited | 2<br>Developing | 3<br>Proficient | 4<br>Advanced | 5<br>Exemplary | Self | Team |
|---|---|---|---|---|---|---|---|
| **Identifies Relevant Facts (*"What do we know?"*)** | Cannot identify facts, or mixes facts with opinions. | | Identifies most relevant facts. | | Helps distinguish facts from opinions/inferences. | | |
| **Asks Relevant Questions ("What more do we want to know?")** | Asks no questions or ones unrelated to script. | | Asks basic kinds of "who, what, where, when" questions. | | Asks higher-level questions which reflect depth of thought. | | |
| **Organizes Questions for Research** | Is unable to organize questions into categories. | | Organizes questions into appropriate categories. | | Identifies questions that fit into multiple categories. | | |
| **Selects Useful Information from Appropriate Sources** | Cannot locate information to answer research questions. | | Obtains relevant information from key sources provided. | | Obtains reliable and wide-ranging information from sources beyond those provided. | | |
| **Organizes and Presents Information Effectively** | Does not organize information to clearly present answers to research question(s). | | Organizes information to clearly present answers to research question(s) | | Summarizes information from many sources; presentation is concise accurate, and insightful. | | |
| **Identifies Major Problem(s) and Stakeholders** | Cannot state a major problem or identify important stakeholders. | | Identifies major problem and major stakeholders. | | Distinguishes between major & minor problems; identifies direct & indirect stakeholders. | | |
| **Develops Multiple Solutions to Major Problem(s)** | States only one (obvious) course of action to major problem. | | Develops two or more solutions to the major problem(s) | | Develops multiple solutions based on pros/cons and stakeholder perspectives. | | |
| **Chooses a Course of Action and Supports Choice** | Cannot select or support a course of action. | | Selects and supports a course of action based on ethics or risks/benefits to one stakeholder | | Selects a solution based both ethics and risks/benefits to multiple stakeholders | | |

Name_____ Members of your team _____

## #2: PBL TEAMWORK AND TEAM PROCESSING RUBRIC

| Team Members: | 1 Limited | 2 Developing | 3 Proficient | 4 Advanced | 5 Exemplary | Self | Team |
|---|---|---|---|---|---|---|---|
| **Distribute Tasks** | Do not distribute tasks equally. | | Distribute tasks equally. | | Distribute tasks based on team members' skills. | | |
| **Collaborate & Contribute Equitably** | Let one or two team members do most of the work. | | Ensure that all team members contribute fully. | | Know and encourage each other's strengths to do quality work. | | |
| **Manage Conflict** | Do not recognize or take action to reduce conflict | | Resolve conflicts to continue to stay "on task." | | Identify and actively use "win-win" solutions to manage conflict. | | |
| **Use Brainstorm "Rules"** | Do not use brainstorm "rules"; allow others to block the process. | | Follow brainstorming "rules" and contribute ideas equally. | | Develop new "rules" as needed to facilitate the brainstorming process. | | |
| **Effectively Reflect on Teamwork** | Do not contribute to discussions about their work as a team. | | Use the results of this rubric to suggest ways to improve teamwork. | | Regularly monitor and assess teamwork of individuals and group as a whole. | | |
| **Build Consensus** | Do not attempt consensus process. | | Use consensus process to work effectively. | | Seek out feedback and process this information to improve teamwork. | | |
| **Manage Time** | Do not monitor their progress or recognize time constraints. | | Use time efficiently and complete all tasks on time. | | Regularly monitor and assess progress to exceed task expectations. | | |
| **Produce Quality Work** | Show no, or limited, attention to making quality products. | | Create high school products that meet expectations | | Create products that resemble practicing professionals "in the field." | | |
| **Stay on Task** | Are easily distracted or frequently go "off task." | | Use time in focused & productive ways. | | Create work-plan agenda and monitor progress. | | |
| **Come Prepared** | Are not consistently prepared with needed materials. | | Are consistently prepared with needed materials. | | Take time daily to assure that materials are ready for next work session. | | |
| **Maintain Positive Attitude** | Exhibit negative behaviors; use "put down" expressions. | | Exhibits positive attitudes/behaviors towards work and others. | | Assist others in maintaining positive attitudes and behaviors. | | |

**PBL Problem Solving and Teamwork Reflection Questions:**

1. Describe a specific example of something you learned from your PBL team (e.g., information or a problem solving or teamwork skill) that you probably would not have learned on your own.

2. Describe a specific example of something that your team members learned from you (e.g., information or a problem solving or teamwork skill) that they probably would not have learned without you on their team.

3. Suggest one specific, practical change the team could make that would improve the team's learning, problem solving or teamwork skills.

## Appendix B

# *Family Secrets* Genetics Test

### Part A

1. The symptoms of many genetic diseases happen because of a change in a gene's base sequence. That change then:
    1. alters the function of the protein produced by that gene.
    2. breaks the weak bonds attaching genes to a chromosome.
    3. causes more frequent fertilizations by deformed gametes.
    4. modifies the gene frequency for that gene in the cell.

2. Which laboratory technique is most likely used to test for a change in the sequence of bases within a gene?
    1. microscopic analysis
    2. gel electrophoresis
    3. chromatography
    4. pH indicators

3. Listed below are 4 events that occur in cells as a result of a mutation.

| A. | B. | C. | D. |
|---|---|---|---|
| Change in the **DNA code** | Change in the **shape of a protein** | Change in the **amino acid sequence of a protein** | Change in **cell metabolism** |

Which sequence of events most accurately represents the order in which these changes normally occur?

1. A, C, B, D
2. B, C, D, A
3. C, D, A, B
4. D, B, A, C

4. Polymerase Chain Reaction (PCR) is a laboratory technique used for replicating DNA molecules. During this PCR process, a DNA molecule serves as a template to:
    1. link amino acids to form a new protein.
    2. cut genes at specific DNA base sequences.
    3. alter genes for recombination.
    4. form a new, complementary strand of DNA.

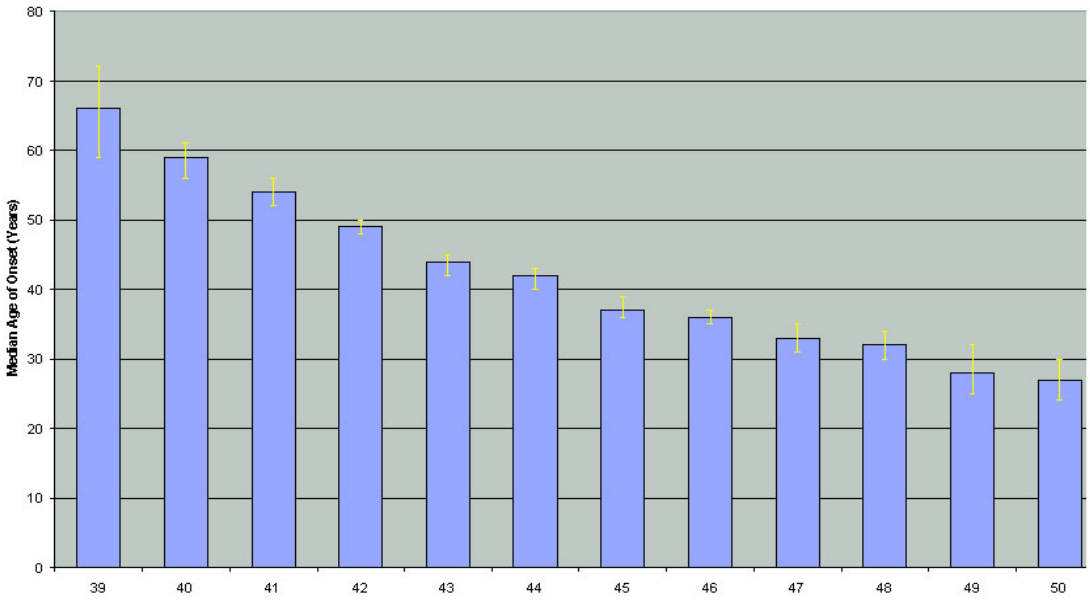
5. Familial ALS, also known as Lou Gehrig's disease, is a lethal, genetic disease caused by a gene mutation. The symptoms of this disease typically begin when affected individuals are in their late 50s. The percentage of the human population affected by familial ALS has remained relatively stable for many years. The most likely explanation for this stability is that:
    1. harmful mutations are not subject to natural selection.
    2. individuals with this disease do not have any mutations.
    3. the symptoms of the disease occur only in males.
    4. affected individuals reproduce before their symptoms appear.

6. Doctor's now have the technology to perform genetic tests on developing embryos to determine if the embryos carry specific genes that cause inherited diseases. One of the main reasons that these genetic tests are <u>not</u> used extensively is that:
    1. it is not possible to obtain genetic material from embryos.
    2. gene testing causes changes in the genetic code.
    3. there are many ethical concerns about this technology.
    4. it is easier to clone embryos that are free from genetic defects.

7. When geneticists perform a test on a patient's genetic material to determine whether it contains a gene for an inherited disease, they often include both a sample from the patient and a sample known as a "positive control". The positive control sample would most likely contain:
    1. genes for other diseases caused by bacteria or viruses.
    2. antibodies that bond to the DNA that causes the genetic disease.
    3. enzymes that digest the protein produced by the gene.
    4. DNA from an individual who has the inherited disease.

8. The information in the graph below was obtained from research on individuals who have inherited the gene that causes Huntington's disease (HD). Huntington's disease is caused by an abnormal number of CAG repeats in the DNA base sequence of the huntingtin gene.

Observed Age of Onset of Symptoms




Number of CAG Repeats

What is the best interpretation of the observed results?

1. A large numbers of CAG repeats is associated with early onset of HD symptoms.
2. As people get older, their number of CAG repeats increases significantly.
3. The number CAG repeats predicts what symptoms an individual will have.
4. Early onset of HD symptoms causes a small number of CAG repeats.

9. Researchers conducted a survey to study the attitudes of the public towards the use of genetic engineering technology. The results in the chart below show the percentages of people who responded to questions about possible reasons to use genetic engineering technology to change a baby's genetic characteristics.

| **Possible reasons to use genetic technology** | **Appropriate use of genetic technology** | **Don't know** | **Taking genetic technology "too far"** |
|---|---|---|---|
| for cosmetic purposes | 4% | 2% | 94% |
| to reduce the risk of serious genetic disease | 41% | 4% | 54% |

Which of the following statements best explains the results of this survey?

1. The use of medical advances to change a baby's characteristics is not legal.
2. Genetic engineering will have no effect on a baby's characteristics.
3. Decisions about using medical advances depend on people's values.
4. Most people support changing a baby's genetic characteristics.

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## Part B

*Base your answers to questions 10 through 12 on the information below and on your knowledge of biology.*

### Huntington's Disease Research: Hope for the future?

Huntington's disease (HD) is a fatal neurological disorder. Symptoms of the disease include rapid, jerky involuntary movements, difficulty in speaking and swallowing, cognitive (mental) decline, and depression. These symptoms are caused by the destruction of cells within specific regions of the brain. As this destruction continues, symptoms appear in the late 40s, and the person dies within 8 to 25 years of the onset of the symptoms.

Huntington's disease is caused by a mutation in gene that codes for the production of a protein called *huntingtin*. Researchers discovered that in the mutant HD gene, molecular "triplets" of Cytosine, Adenine, and Guanine (CAG triplets) are more abundant than they are in the normal gene. In normal (unaffected) people, the CAG triplets repeat between 10 and 35 times. In HD (affected) people, the CAG triplets repeat between 40 and 100 times.

The CAG triplet codes for the amino acid glutamine. Therefore, the abnormal form of the *huntingtin* protein has a longer-than-normal repeating stretch of this amino acid. This longer glutamine stretch causes the protein to have a misfolded structure that, in turn, causes it to bind tightly to a specific protein (known as HAP-1) found in certain brain cells. This binding causes these brain cells, over time, to malfunction and be destroyed.

Scientists have developed a genetics test that can detect the mutation that causes HD. This genetic test can identify people who are at risk of developing the disease symptoms. Researchers are studying the structure and function of the lethal *huntingtin* gene in hopes of controlling and preventing HD. Scientists hope to find new therapies to prevent the harmful interactions between abnormal *huntingtin* and HAP-1. Currently, however, there is no cure or treatment for Huntington's disease.

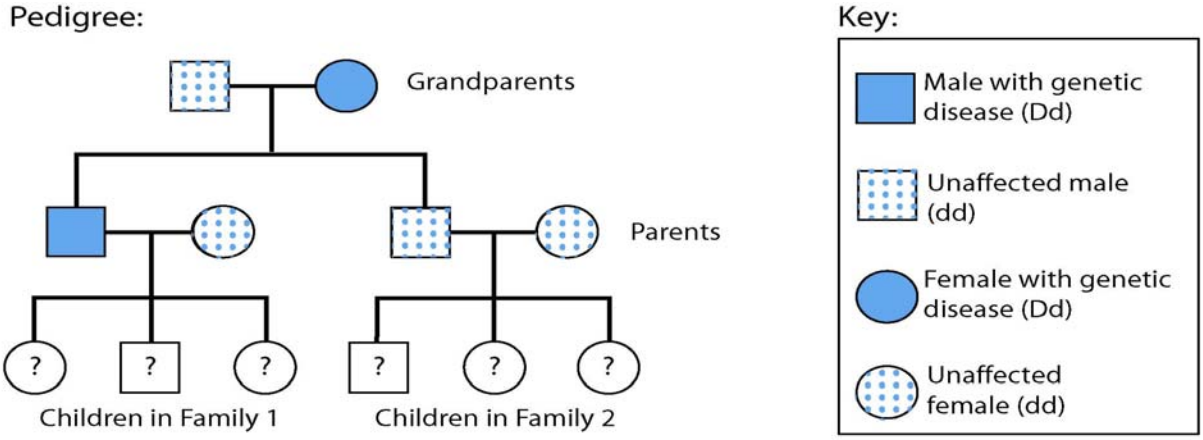
10. The normal *huntingtin* gene and the mutant *huntingtin* gene that causes Huntington's differ in their:
    1. amount of HAP-1
    2. DNA base sequence
    3. amino acid shape
    4. amount of glutamine

11. The mutant gene most likely leads to the symptoms of Huntington's disease because the HD gene codes for a protein that:
    1. occurs in sex cells but not in body cells
    2. has a different shape and function
    3. results in gametes that lack chromosomes
    4. is expressed in males but not in females.

12. As a test for the gene that causes Huntington's disease, scientists would most likely:
    1. look for symptoms of mental decline and depression
    2. measure the concentration of glutamine in the blood and brain
    3. prevent interactions between HAP-1 and *huntingtin* protein
    4. identify the number of CAG triplets in the *huntingtin* gene

***Base your answers to questions 13 through 15 on the information below and on your knowledge of biology.***

The children in Family 1 and Family 2 have a family history of a genetic disease known as "familial hypercholesterolemia." This genetic disease is caused by a gene mutation. Individuals with one defective gene have high blood cholesterol levels which puts them a risk of early heart disease. Genetic testing can be done to reveal whether children have inherited the defective gene for "familial hypercholesterolemia."




13. When people have a family history of a familial hypercholesterolemia, doctors usually suspect that the symptoms of the disease are caused by
    1. a defective base sequence in DNA
    2. increased exposure to viruses
    3. antigens produced by bacteria
    4. vaccinations that trigger an immune response

14. Which statement best describes the children's risk of developing familial hypercholesterolemia?

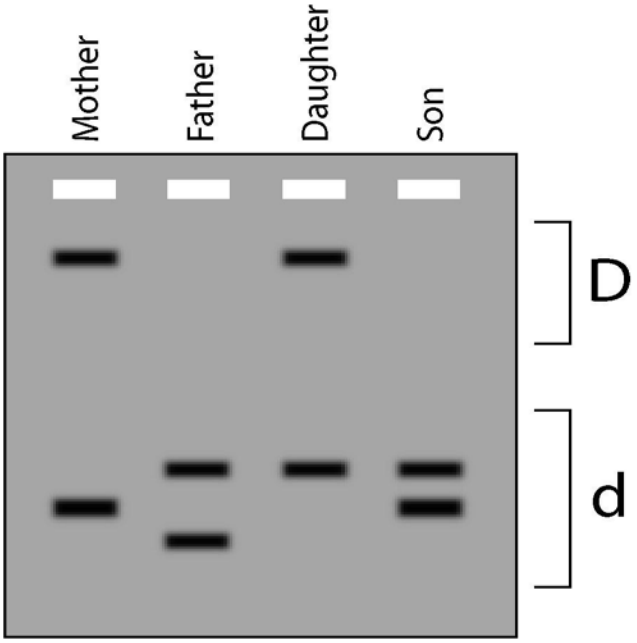
1. The children in both Family 1 and Family 2 are at a 25% risk because genes can "skip" generations.
2. All of the children in Family 2 are at a 100% risk of inheriting the gene that causes the disease.
3. Each child in Family 1 has a 50% chance of inheriting the gene that causes the disease.
4. It is not possible to determine if the children in Family 2 are at risk.

15. Which genetic concept best explains the fact that two parents who have familial hypercholesterolemia can produce offspring who do NOT have the disease?

1. Radiation and certain chemicals cause mutations.
2. Meiosis and fertilization result in new gene combinations.
3. Natural selection increases the frequency of beneficial genes.
4. Cloning produces identical genetic copies.

***Base your answers to questions 16 through 18 on the diagram below which shows the results of genetic testing for polycystic kidney disease.***

Polycystic Kidney Disease (PKD) is an inherited condition caused by a dominant gene mutation. An individual with one or two genes for this disease will typically develop symptoms at approximately age 50. These symptoms include cysts in kidneys, bloody urine, high blood pressure, and abdominal pain.




At least one band in the **D** range occurs in individuals who will develop polycystic kidney disease.

Two bands in the normal **d** range occur in individuals who do not have the gene for polycystic kidney disease.

16. Which statement is supported by the information in the diagram?
    1. The mother may develop polycystic kidney disease
    2. The father has two disease causing genes
    3. The daughter will not develop polycystic kidney disease.
    4. The son received two normal genes from his father

17. The diagram illustrates the use of what laboratory technique?
    1. dichotomous keys
    2. chromatography
    3. gel electrophoresis
    4. pH indicators

18. The technique illustrated in the diagram is used to
    1. cut genetic material
    2. remove extra chromosomes
    3. replace defective genetic material
    4. separate fragments of DNA

***Base your answers to questions 19 through 21 on the information below and on your knowledge of biology.***

Sickle cell disease is caused by a recessive mutation in the gene that codes for hemoglobin, a protein found in red blood cells. Individuals with sickle cell disease have two defective genes. Symptoms of the disease typically include fatigue, joint pain, spleen damage, and high risk of infection. The diagram below illustrates the result of genetic testing performed on 3 family members suspected of having the gene that causes sickle cell disease.

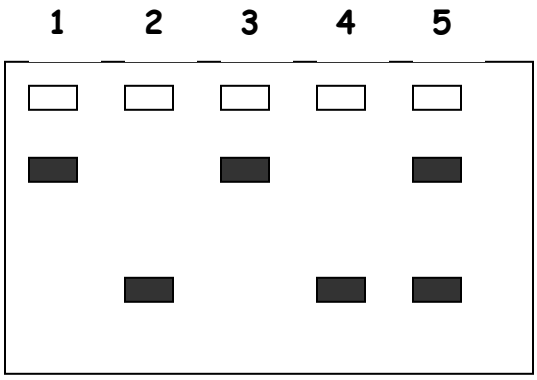
**1** = DNA from individual with sickle cell disease

**2** = DNA from unaffected individual

**3** = DNA from Mother

**4** = DNA from Father

**5** = DNA from Daughter




19. Why did the DNA from the father move farther through the gel than the DNA from the mother? [1 credit]

20. Explain why the DNA from the daughter produced two bands rather than one. [1 credit]

21. The mother has a sickle cell disease. Her daughter does not have sickle cell disease. Give a genetic reason why this is possible. [1 credit]

## Part C

People who have a parent with a genetic disease can find out whether or not they have inherited the gene for that disease by having a genetic test. In order for to make an informed decision about genetic testing, they should understand that their decision may have both positive consequences (benefits) and negative consequences (risks).

22. State one positive consequence (benefit) that could result if you decided to be tested to determine if you had a gene for an inherited disease. [1 credit]

23. State one negative consequence (risk) that could result if you decided to be tested to determine if you had a gene for an inherited disease, **AND** explain why this consequence would be considered a "risk." [2 credits]