

# ***Family Secrets***

## **Part 2 The Dilemma**

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*Narrator: Jenny had expected the doctor to give her some kind of lab test. But instead, the doctor began to talk to them about her grandmother's disease.*

Dr. Day: Let me review this one more time to make sure I understand the facts. Jenny and Jeremy's grandmother just passed away. She was your ex-husband's mother and we know that she had Huntington's Disease. Your husband is not having any problem with his health at this time, but since he is relatively young, he could have the HD gene and not show any symptoms of the disease yet. He doesn't want to get tested, so we don't know if he has the HD gene or not. You want Jenny tested so you can help her prepare for her future. Is that pretty much it?

Mother: Yes, doctor. But I need to know how much testing costs. Does my insurance pay for it?

Dr. Day: Before we have that discussion, there are a number of other things we need to discuss first. However, before you and I talk, I would like to talk to Jenny privately for a moment, if you don't mind."

Mother: Well.....I guess that would be okay. I'll be in the waiting room.

Dr. Day: Jenny, I know what you are going through with your grandmother passing away. You should know that the last thing your grandmother would have wanted is for you to be sad. You heard what your mother and I were discussing just now. What do you think of all this?

Jenny: I don't know what to think. I know my mother wants the best for me. I loved my Grandma, but the last few years really made me scared about her Huntington's disease. Grandma was so helpless! When my mother told me I was going to get tested to see if I'll get the same disease, it really scared me. I don't know anything about this test. What happens if the test says I'll get Huntington's?

Dr. Day: Jenny, first, let me reassure you that I'm not going to give you a gene test today. Genetic testing requires informed consent from the person being tested. Because you are 16, and are legally considered a minor, testing for Huntington's disease is not recommended. You shouldn't be tested until you are 18 and can make this decision for yourself. I'll explain this to your mother before you leave.

Jenny: But I don't like thinking about getting this disease.....

Dr. Day: You're right. Worrying you may develop Huntington's disease is scary. You should know that some people decide to be tested and others, like your father, decide not to be tested. The decision about whether or not you should be tested for Huntington's disease is a very difficult one, but it's one you will need to make.

Jen: From the way Mom and my friends talk, I thought everybody got tested. Can you explain why my Dad refuses to get tested?

Dr. Day: No, because of doctor-patient confidentiality, I'm required to keep that conversation private. But it might be a good idea for you to ask him that question yourself. Many people with a family history of Huntington's disease spend years thinking about whether or not to be tested, so you should not rush into any decision.

Jenny: Mom and Dad never really explained much to me.....

Dr. Day: You need to learn more about Huntington's disease and learn more about genetic testing. You also need to think about what kinds of choices you could make and what the consequences of each of these choices could be. To help you with this, I'm going to recommend to your mother that she make an appointment for you to meet with a genetic counselor.

Jen: Uh, I don't think that my Mom will do that. She really doesn't like the idea of counselors getting involved in family stuff.

Dr. Day: Then I'll need to be sure that both you, and your mother, understand what genetic counselors do. They help people understand the information that they need so that they can make an informed choices for themselves. Genetic counselors don't tell people what to do. They are trained to help you think about how getting tested or not getting tested might affect your future and your family.

Jenny: Mom and Dad never really explained.....Talking to somebody who could answer my questions might help.

Dr. Day: Let's talk to your mother about scheduling a chance for you to meet with a genetic counselor. Do you have any questions for me before I talk to your mother?

## Part 2 *Family Secrets* - Record of Individual and Team Work

Name: \_\_\_\_\_

Class: \_\_\_\_\_

### **FACTS**

**What are the facts of the case?**

## Part 2 *Family Secrets* - Record of Individual and Team Work

Name: \_\_\_\_\_

Class: \_\_\_\_\_

### Questions

What questions do you have, or think others might have, about the case?

## Parts 1 and 2 *Family Secrets* - Individual Research Log

Name: \_\_\_\_\_

Class: \_\_\_\_\_

**Category**

**Category Question(s) for your research:**

**Source used:** \_\_\_\_\_

**What I found out:**

**Source used:** \_\_\_\_\_

**What I found out:**



**Source used:** \_\_\_\_\_

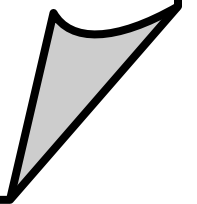
**What I found out:**



**Parts 1 & 2 *Family Secrets* - Category Specialist Report Plan**

Name \_\_\_\_\_ Class \_\_\_\_\_

**What information will you present to your PBL team or to the class.**



Name \_\_\_\_\_ Members of your team \_\_\_\_\_

### #1: PROBLEM SOLVING RUBRIC

Student:	1 Limited	2 Developing	3 Proficient	4 Advanced	5 Exemplary	Self	Team
<b>Identifies Relevant Facts</b> (“ <i>What do we know?</i> ”)	Cannot identify facts, or mixes facts with opinions.		Identifies most relevant facts.		Helps distinguish facts from opinions/inferences.		
<b>Asks Relevant Questions</b> (“ <i>What more do we want to know?</i> ”)	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.		
<b>Organizes Questions for Research</b>	Is unable to organize questions into categories.		Organizes questions into appropriate categories.		Identifies questions that fit into multiple categories.		
<b>Selects Useful Information from Appropriate Sources</b>	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.		
<b>Organizes and Presents Information Effectively</b>	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.		
<b>Identifies Major Problem(s) and Stakeholders</b>	Cannot state a major problem or identify important stakeholders.		Identifies major problem and major stakeholders.		Distinguishes between major & minor problems; identifies direct & indirect stakeholders.		
<b>Develops Multiple Solutions to Major Problem(s)</b>	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.		
<b>Chooses a Course of Action and Supports Choice</b>	Cannot select or support a course of action.		Selects and supports a course of action based on ethics <u>or</u> 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**

<b>Team Members:</b>	<b>1 Limited</b>	<b>2 Developing</b>	<b>3 Proficient</b>	<b>4 Advanced</b>	<b>5 Exemplary</b>	<b>Self</b>	<b>Team</b>
<b>Distribute Tasks</b>	Do not distribute tasks equally.		Distribute tasks equally.		Distribute tasks based on team members' skills.		
<b>Collaborate &amp; Contribute Equitably</b>	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.		
<b>Manage Conflict</b>	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.		
<b>Use Brainstorm "Rules"</b>	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.		
<b>Effectively Reflect on Teamwork</b>	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.		
<b>Build Consensus</b>	Do not attempt consensus process.		Use consensus process to work effectively.		Seek out feedback and process this information to improve teamwork.		
<b>Manage Time</b>	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.		
<b>Produce Quality Work</b>	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."		
<b>Stay on Task</b>	Are easily distracted or frequently go "off task."		Use time in focused & productive ways.		Create work-plan agenda and monitor progress.		
<b>Come Prepared</b>	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.		
<b>Maintain Positive Attitude</b>	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.

# Informed Consent Form

## Huntington's Disease Direct Genetic Test

Modified from document at <http://www.healthsystem.virginia.edu/internet/hunt/disease/appendix.cfm>

I understand that the gene for HD has been found and is located on Chromosome 4. It has been described as having a trinucleotide (CAG) repeat mutation. It is the size of this trinucleotide repeat which determines whether or not HD will be expressed. The blood test will determine the size of this CAG repeat.

I understand that there can be three outcomes to my test:

1. Negative: I will be told that the CAG repeat size is in the normal range (35 or fewer repeats) and that I am not likely to develop HD.
2. Positive: I will be told that the CAG repeat size is expanded into the HD range (40 or more repeats) and that I am highly likely to develop HD at some point in my life.
3. Uninformative: I will be told that the CAG repeat size is in the intermediate range (36-39 repeats) and that it is unclear whether I will or will not develop HD at some point in my life.

I understand that a positive test result cannot tell me when I will begin showing signs of HD. I understand that the diagnosis of the onset of HD can only be made through a neurological exam.

If available, it is recommended that this blood test first be performed on an affected family member in order to confirm the presence of HD in my family.

I agree to participate in the counseling sessions and neurologic exam required for the test. Sessions will last from one to three hours. I am aware that the neurological examination may disclose that I have clinical signs of Huntington's Disease. Time between sessions will vary depending upon my own desire for space between visits and the number of other people scheduled for testing and neurologic consult. I understand that during this time I will take part in psychological evaluations, including in-depth interviews regarding my attitudes toward predictive testing, how I could react to various test outcomes, my personal relationships, how I would handle these and other aspects of psychological functioning which have a bearing on the testing procedure.

I agree to have a neurological exam. I am aware this examination may show that I have clinical signs of HD and I will be told of my results if I so request. The neurological exam can also sometimes be indeterminate and an accurate diagnosis may require further exams at later dates.

I agree to select and meet with a local therapist (social worker, psychologist, psychiatrist, minister). I understand it is critical to have this emotional support in place before the test results are given; you will help me to identify an appropriate therapist in my area, if requested. This person should be someone whom I can trust and feel comfortable discussing HD with. I agree to provide the name of this person to you so that you can contact this person and let him/her know that the members of the Huntington's Disease team will serve as a resource regarding HD. At least one follow-up session with the HD team

psychologist is recommended with a positive test result. More may be requested as they are needed and desired.

I am fully aware that my decision to seek testing in the program is wholly voluntary and that I can choose to withdraw at any time without jeopardy to my medical care. If I decide to withdraw from the program, I agree to at least one visit with the test staff following my decision. I also understand that the HD program staff may decide to postpone my testing. The reasons for doing this will be fully explained to me.

I understand that I am encouraged to have a companion of my choice to act in a support-giver capacity. This companion may accompany me through the entire program or parts of it as I choose.

The risks of such testing are primarily psychological. A negative result, indicating that I am not likely to develop HD, can produce feelings of guilt as well as joy. A positive result, indicating that the HD gene is present, could lead to serious psychological consequences including feelings of depression, futility, despair, and severe stress. An uninformative outcome can be frustrating and can intensify the ambiguity of the risk situation or can provide relief. Counseling provided during the testing process is designed to help me adjust as well as possible to negative, positive, or uninformative information. Counselors will discuss with me other possible risks such as difficulties with confidentiality, employment, or insurance.

Physical risks include the discomfort of a needle prick and the possibility that a bruise may form of a result of blood being drawn.

I understand that I will be responsible for the costs of testing, which should be about \$1500-2000 on average. Some of these costs may be covered by third-party coverage, but insurance payment will require disclosure of test information.

I understand that all information will be held strictly confidential. The results of testing will be given only to me, in person, and will be released only with appropriate consent from me or other appropriate legal consent. I understand that DNA testing results, as with all genetic information, may adversely affect my employment, ability to keep or maintain insurance and/or rates of insurance coverage. I am aware that although your lab will maintain confidentiality of samples and test results, you cannot guarantee that this information will not be obtained by subpoena by other third parties. I also understand that information about myself/family member's test results may be requested by family members/myself by third parties and that failure to give this information may be considered fraudulent.

Results from this clinical genetic testing will be sent by written report to the referring professional. They will discuss the results, the laboratory interpretation and answer questions. Testing center staff will be available to discuss testing protocol/methodology, test results and interpretation and to answer questions if needed.

Results will NOT be entered by us into your medical record and is stored in our files with a code number identifier only. Access to these records is restricted in accordance with applicable laws. You should be aware that genetic information, including molecular DNA test results, may influence insurance and/or employers regarding your health status.

Information obtained from the test may be used in scientific publications, but the identity of all persons in the test will not be revealed in such publications or in any other report. I have given accurate information about the biological relationships of my family members to the best of my ability and understand that incorrect information may result in an incorrect diagnosis. I also understand that DNA testing on multiple family members may indicate that a person named as a father of an individual may not be that individual's biological father (i.e., non-paternity).

Despite the highly accurate nature of this testing and laboratory quality control measures, errors (false positives and false negatives) may occur at a frequency estimated to be less than 1%.

We currently do not offer presymptomatic DNA testing to those under the age of 18 years. We do offer fetal testing and pre-implantation diagnostic testing for IVF embryos. My signature on this form signifies that I have decided to participate in this testing program after reading the above information. I have been given the opportunity to discuss pertinent aspects of the testing program, to ask questions, and hereby consent to participation in the testing outlined above.

Indicate below whether you agree, or do not agree, to be tested to see if you have the HD gene.

- I REQUEST predictive testing for the presence of the Huntington's Disease gene.
- I DO NOT REQUEST to have predictive testing for the presence of the Huntington's Disease gene.

Patient name (please print) \_\_\_\_\_

Patient signature \_\_\_\_\_ Date \_\_\_\_\_