

# **Family Secrets**

A Problem-Based Learning Case

## Part 3

# A Difficult Choice

# Family Secrets

## Part 3 A Difficult Choice

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*Narrator: It's now 5 years later. Jenny meets her dad to celebrate her 21<sup>st</sup> birthday. She finally feels confident enough to ask her Dad the question that's been on her mind for a long time.*

Dad: I'm glad we could meet for lunch. Twenty-first birthdays call for a special celebration.

Jenny: Dad, turning twenty-one is really special for me, but it's also scary. Mom's having a family party for me tonight, but tomorrow I have my first appointment with a genetic counselor. And I think Jeremy made an appointment too.

Dad: Does that mean you decided to get tested?

Jenny: I don't know. I've been doing a lot of reading about Huntington's. It's really scary, and there's a lot I still don't understand. Now that Jeremy and I are both old enough to get tested, Mom is really pressuring us.

Dad: Remember it's not her choice.....It's one you and Jeremy need to make.

Jenny: Dad, I don't want to upset you, but I really need to understand why you never got tested. It's important to hear your side of things before I make my decision.

Dad: It's tough to explain. At first they didn't really know why your grandmother's personality was changing. When the doctors finally figured out she had Huntington's, there wasn't any test for the gene. Once they had the test, I'm not sure why I didn't get tested. Your mother used to tell me I hid from the problem, hoping it would go away. She wanted me to face the future and plan for it. But I didn't think I could handle knowing. Your Grandma needed me, and I couldn't imagine taking care of her if I knew that I would suffer like she did. Even worse, I couldn't bear thinking I might have passed the gene to you or to Jeremy. I wish I'd known about Grandma's illness before we had you and Jeremy.

Jenny: But you could have gotten tested and found out that you didn't have the gene. Wasn't it worse to live with the uncertainty—to not know?

Dad: Maybe, but there was the possibility that I did have the gene and there were other reasons why I didn't want the test.

Jenny: Like what?

Dad: I couldn't be sure that other people won't find out about my test results. Imagine what the airline I work for would do if they found out one of their pilots had the gene? What would my health insurance company do? There are some laws about privacy and discrimination but I wasn't sure they would really protect me.

Jenny: One article I read said that people could avoid that kind of problem by paying for their genetic testing by themselves so their insurance company and employer wouldn't find out the results.

Dad: But even if you do that, it would still be a risk to tell anyone the results of the test. Think about who you should tell, and then who they might tell. Your mother? Jeremy? Your friends? Keeping all this as a family secret was the safest thing for me to do.

Jenny: I know about family secrets. You and Mom raised us to say that Grandma had mental problems. We weren't supposed to talk about Huntington's. Now I understand that you and mom did that to protect us. But it would have been nice to ask my friends for their advice.

Dad: And speaking of friends. What are you going to do if you start dating someone seriously? When should you tell him? Or even should you tell him? Getting tested doesn't stop the questions; it simply changes the questions that you need to deal with.

Jenny: Maybe I should wait until I've found a boyfriend that I'm really serious about. Or maybe I should even wait until after I'm married and want to have children. Then my husband could help me decide. Maybe by then they'll have a cure.

Dad: Would that be fair to him?

Jenny: No. I guess not. Talking to you has just made this more complicated. But I guess that's good. It makes me realize that I really need to think about the pluses and minuses for all my options.

Dad: Jenny, there is something else you and Jeremy need to know. I have been having some problems lately. I'm getting angry and depressed more often, and I've been noticing these small muscle twitches. I finally went to Dr. Day, and she told me that these might be early signs of Huntington disease. I'm getting tested to be sure. I mailed the Informed Consent Form back to the genetic counselor today. But I think I know what the results will be.

Jenny: I'm so sorry. I hope you're wrong. I hope you'll let us know the results.

Dad: I'm really glad you and Jeremy are seeing a genetic counselor. The counselor will probably add a few more things for you to think about. Make sure you read the Informed Consent Form carefully and ask all your questions before you make your decision.

Jenny: I hope the genetic counselor will help me make a list of the pros and cons for having a genetic test.

# Ethical Decision-Making Process

**Work as a whole class to discuss and complete Steps 1-3**

1. What is the ethical problem or dilemma?

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2. Identify the stakeholders who may be affected by the problem.

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3. List others who could assist or influence the stakeholders in making the decision.

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**Work as a Team to discuss Steps 4-6  
and complete the chart on the next page**

4. Describe at least three possible courses of action and record these on the attached Ethical Decision-Making Chart on the next page.
5. Describe the benefits (pros) and risks (cons) of each course of action on the Ethical Decision-Making Chart on the next page.
6. Identify the ethical principles and values which support each course of action on the Ethical Decision-Making Chart on the next page. Refer to the Principles and Values Chart.

# Ethical Decision Making Chart

Ethical Question being discussed:

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Course of Action	Pros (benefits)	Cons (risks)	Principles	Values



## ***Family Secrets Part 3: A Difficult Choice*** **Quick Guide for Sample Lesson Sequence**

### **Overview**

PBL Part 3	Class #	Check Off	Time	Strategy / Activity Name
A Difficult Choice	5			Assess Prior Knowledge • Half Sheet of 2 Definitions and Reports
				Rank Ordering Ethical Principles, "Top 3" Values, with "real life" student examples
				Bioethical Dilemma Word Splash Posters
	6			Script Reading: Part 3
				Quick Team Brainstorm
				Intro to Ethical Decision-Making Process (EDMP)
				Whole Class work: EDMP Steps 1-3
				Team work: EDMP Steps 4-6
	7			Individual work: EDMP Steps 7-8
				Topical Barometer #2 (with only 2 choices)
				Barometers "conversation" and conclusions
				<u>Either</u> : Discussion of Topical Barometers and/or Step 8 decisions and rationale <u>Or</u> : Practice gel loading

### **You will need**

#### **For Each Student:**

- Student folders from Parts 1 and 2
- 1 Post-It Note
- 1 copy per student of
  - *Assessing Prior Knowledge* (see Part 3: Appendix B)
  - *Family Secrets Part 3: A Difficult Choice* script
  - *Ethical Principles and Values Charts* (see Part 3: Appendix C)
  - *Ethical Decision-Making Process Model Worksheet*

#### **Per Team:**

- Team Facts and Questions charts from Parts 1 and 2
- 1 poster and marker per team for Ethical Dilemma Word Splash poster

#### **Per Class:**

- Three highlighted copies of Part 3 script, one per reader: Narrator, Jenny, Dad
- 1 old "Topical Barometer" from Part 1
- 1 new, modified "Topical Barometer" for Part 3

## **Class 5**

- Students complete *Assessing Prior Knowledge* (Part 3: Appendix B)
- Discuss ethical principles using *Ethical Principles Chart* (Part 3: Appendix C)
- Teams complete example column, then individuals rank order 4 major Ethical Principles
- Discuss ethical values using *Ethical Values Chart* (Part 3: Appendix C)
- Individuals rank order three most important (“top 3”) Values
- Discuss definition and give examples of Ethical Dilemmas; stress the “competing value systems”
- Teams complete *Bioethical Dilemma Word Splash Poster* (Part 3: Appendix D) as another form of assessing prior knowledge, this time about examples of ethical dilemmas and concepts associated with them.

## **Class 6**

- Class reads Part 3 script. Assign readers: Narrator, Jenny, Dad.
- Teams do a quick brainstorm of new Fact and Questions from the reading.
- Whole class discusses and completes Steps 1-3 of Ethical Decision-Making Process (answers should all be the same).
- Teams work to complete Steps 4-6 of the Ethical Decision-Making Process (answers will vary among teams)

## **Class 7**

- Individuals complete Steps 7 and 8 on *Ethical Decision-Making Process Model Worksheet*
- Collect *Ethical Decision-Making Process Model Worksheet*
- Class completes new, modified Post-It “Topical Barometer,” this time with only 2 choices: definitely yes, or definitely no.
- Students compare the Part 2 and Part 3 “Topical Barometers.
- Optional: Students who changed their position explain why they changed.
- Optional: Volunteers read their position statements to the class—include both pro and con statements
- Optional: students practice gel loading

Optional homework: Look at the Dolan Learning Center website <http://www.ygyh.org/hd/whatisit.htm> or the DNAi website <http://www.dnai.org>



# *Family Secrets*

## **Part 3 - A Difficult Choice**

### **Detailed Instructional Guide**

#### **Overview**

Jenny meets her dad for lunch to celebrate her 21<sup>st</sup> birthday. She tells him of her decision to go see a genetic counselor, and finds out, for the first time, some of the reasons why he never got tested. Dad gets Jenny to see that her decision will affect others, and carries with it both benefits and risks that she had not anticipated. In Part 3, students become aware that choices are difficult because they involve ethical, legal, and social implications that affect more than just themselves. They are introduced to a multi-step ethical decision-making model, and use this model to begin the process of figuring out what they would do if they were Jenny. They are introduced to the four major ethical principles of autonomy (freedom to choose), justice (playing fair), beneficence (doing good), and non-maleficence (avoiding harm), and some values such as confidentiality and privacy, honesty, fidelity, and integrity.

#### **Objectives**

After completing Part 3, students should provide evidence that they have:

- Identified the ethical problem or dilemma that Jenny faces
- Selected appropriate ethical principles and values associated with some ethical, legal, and social implications of her decision about gene testing
- Identified the stakeholders related to Jenny’s decision.
- Outlined various courses of actions that Jenny may take.
- Analyzed the benefits/pros, risks/cons, and limitations of courses of action related to gene testing.
- Produced a piece of writing that summarizes their reasons for their course of action related to whether or not to be tested if they were Jenny.
- Participated in a post-activity “Topical Barometer.”

#### **Coach’s Preparation**

Coaches should carefully review the information on Main Concepts related to ethical issues provided in Appendix A. They should also work to complete the *Ethical Decision-Making Process Worksheets* so that they understand what students will be experiencing during Part 3. The ethical decision-making model from this PBL may be used during other parts of the course in which ELSI issues might surface (e.g., health care, the environment, or medical research into areas such as stem cells). It is recommended that

the *Ethical Decision Making Process Worksheet* be used with one of these issues prior to doing *Family Secrets* so students are aware of the steps in the process. Coaches should become familiar with, and have teenage examples of, the four major ethical principles and selected values vocabulary. The focus of this Part of the PBL should be on Jenny's decision related to being tested for the HD gene.

In addition, coaches should:

- Read and select printed and/or Internet resources for student research. See Part 3: Appendix A.
- Make copies of Part 3 script, one copy per student.
- Copy the *Assessing Prior Knowledge* half sheet, one per team (See Appendix B).
- Copy the *Ethical Principles and Values Charts*. See Appendix C.
- Copy the *Ethical Decision-Making Process Worksheets*, one copy per student
- Make a Post-It Note wall chart "Topical Barometer" or use the one from Part 1. Provide Post-It notes for students.
- Review and have available the Virtual Laboratory - Part 2 *Virtual Genetic Testing Procedure for Huntington's Disease*. Depending on computer access, this can be done as a demonstration or as a student activity.

Teachers are encouraged to have students do all of the next part, Part 4 – Testing for the HD Gene. Some teachers have opted to pre-cast the agarose gels for students to save classroom/laboratory time. Note: This significantly increases teacher preparation time. If you are doing the one period Part 4 lab procedure using pre-cast gels, you will also need to prepare for Class 7 by:

- Making one copy of the Practice Gel Loading Instructions. See Part 4.
- Assembling materials for practice gels: practice gels, pipettes, dyes. See Part 4 Coach's Guide for information on preparing practice gels.

### **Concepts for class discussion: background or supporting lessons**

Students need to understand the concepts listed below. Lessons on these concepts may be completed before Part 2 or may be provided as supporting lessons during Part 3.

- Definitions of ethics, bioethics, and morality
- Basic vocabulary dealing with ethical principles and values (see below)
- Decision-making models used in other school subject areas
- The Ethical Decision-Making Process Model (see below)
- The role of a genetic counselor
- Samples of "informed consent" forms

### **The four Major Ethical Principles (and one "teenage example" of each)**

Those working in the field of ethics have identified the following concepts as the four “major” ethical principals. There is no hierarchy of importance intended in the listing; they are presented in alphabetical order. Implied in the column called “Definition” is the concept that each of these principles is directed towards both “self” and “others.” For example, autonomy involves both the freedom to make one’s own decisions and letting others have the freedom to make their own decisions.

<b>Major Ethical Principle</b>	<b>Definition</b>	<b>Teenage Example</b>
<b>Autonomy</b>	Freedom to make one’s own decisions	Choosing a career or college that’s different from one that your family or friends recommend.
<b>Beneficence</b>	Doing what is best	Deciding to exercise on a regular basis.
<b>Justice</b>	Being fair	Deciding to do your own homework rather than copying it from a friend.
<b>Nonmaleficence</b>	Avoiding harm	Deciding to not spread gossip.

### **Some values used in ethical discussions**

Ethicists have identified other concepts that are also important in ethical discussions. Some, but not all, of those concepts are shown in the values list below.

<b>Value</b>	<b>Meaning or Definition</b>
Compassion	Empathy for and actions to relieve other’s suffering
Confidentiality	Keeping a secret
Fidelity	Keeping a promise; fulfilling obligations and duties
Golden Rule	Treating others only as you consent to being treated
Honesty	Telling the truth
Integrity	Conforming to one’s ethical principles and moral values
Privacy	Kept from public view
Respect	Regard for the dignity of self and others

### ***Family Secrets* Ethical Decision-Making Process Model**

There are many approaches, processes, and models used to discuss ethical problems. We have chosen to modify the process used at the University of Rochester School of Medicine and Dentistry. This 8-step *Ethical Decision-Making Process Model* is a comprehensive method that can be used to systematically address ethical issues. The 8

steps of this model are listed below, and can also be found with embedded worksheet charts as part of the *Ethical Decision-Making Process Worksheet* in Part 3 of *Family Secrets*. Steps 1-3 are to be completed by the whole class. Steps 4-6 are to be completed by the PBL team. Because steps 7 and 8 involve personal choices and reasoning, they are to be completed individually by each student.

### **Whole Class Work Steps:**

1. Identify the question being discussed, and describe why it is an ethical problem.
2. Identify and list any stakeholders who may be affected by the problem.
3. List the people who could be involved in selecting a course of action or in assisting or influencing the stakeholders in selecting a course of action.

### **Team Work Steps:**

4. Describe possible courses of action. Include possibilities that are obvious, subtle, and “off-the-wall”, even ones that might have obstacles. Think along a continuum of possibilities, not just in an “either-or” mode.
5. Use a decision making chart to describe the benefits (pros) and risks (cons) of each course of action.
6. Identify the ethical principles and values that support each course of action.

### **Individual Work Steps:**

7. Rank-order the ethical principles and values according to their importance to you.
8. Identify your choice for the best course of action. Support your choice by using your rank order of the ethical principles and values to explain the reasons for your choice. Your reasons may also include a discussion of the benefits and risks related to your choice.

### **Coaching Questions that might be used to assist students during the decision-making process:**

- What should Jenny know before she can make an informed decision?
- Who might be affected by the decision that Jenny makes?
- Who might help Jenny make the decision?
- What are Jenny’s options/alternatives?
- What are the risks/benefits of each option?
- Why is making this decision difficult for Jenny?
- What would you do if you were Jenny? Why?
- What are the “trade-offs” or compromise decisions that Jenny might make?
- Why might someone else make a different choice?

## Sample Lesson Sequence: Part 3: A Difficult Choice – Classes 5, 6, 7

Estimated Time (min.)	Summary Steps	Suggested Strategies
<b>Class 5</b>		
-	On front board or overhead	<i>"Think of a time when you made a decision you wish you had given more thought to...or more thought to the consequences of your decision?"</i>
5	Assessing Prior Knowledge - 1	<ul style="list-style-type: none"> <li>Coach posts on flip chart or overhead the following directions: <i>Get into your PBL Teams. Take 5 minutes to jot down some ideas that come to mind, either from your research so far in your teams, or from your personal background, when you hear the following terms <b>ethics</b>, <b>bioethics</b>.</i> Fill out the Family Secrets Part 3 half-sheet with your team's names and your team's ideas about these two terms.</li> <li>Students complete <i>Assessing Prior Knowledge</i> sheet. (Part 3: Appendix B).</li> <li>Coach lists two terms on the board /chart/ overhead</li> </ul>
5	Report	<ul style="list-style-type: none"> <li>Teams report concepts and ideas related to the two terms.</li> <li>Coach writes concepts next to two terms, and collects each team's <i>Assessing Prior Knowledge</i> half-sheet.</li> </ul>
15	Complete Principles and Values Charts	<ul style="list-style-type: none"> <li>Coach uses <i>Ethical Principles Chart</i> to discuss the 4 major ethical <u>principles</u>. (Part 3: Appendix C)</li> <li>Coach asks teams to complete fourth column of chart with one or two examples of each principle.</li> <li>Coach asks <u>individual</u> students to rank the principles in order of importance to their lives.</li> <li>Coach uses <i>Ethical Values Chart</i> (Part 3: Appendix C) to discuss <u>values</u> listed.</li> <li>Coach asks teams to complete fourth column of chart with one or two examples of each value.</li> <li>Coach asks <u>individual</u> students to rank the "<u>top three</u>" values in order of importance to their lives.</li> </ul>

15	<p>Connection to Student's World</p> <p>Assessing Prior Knowledge – 2</p> <p>Bioethical Dilemma Word Splash Poster</p>	<ul style="list-style-type: none"> <li>• Coach defines <b>ethical issue or dilemma</b> as a situation that required a decision or an action that resulted from competing value systems or ethical principles.</li> <li>• Coach models by giving an example (if possible and if comfortable) from her/his own life. Possible examples might include choice of a college or career, changing religious affiliation, or speeding to be on time for a meeting.</li> <li>• Coach asks students to identify other examples of bioethical issues by completing the <i>Bioethical Dilemmas Word Splash Poster</i> (Part 3: Appendix D)</li> <li>• If time permits, coach runs a Round Robin listing of team's Word Splash examples.</li> </ul>
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Class 6		
3	Purposes	<ul style="list-style-type: none"> <li>• Coach explains the <b>purposes</b> for today's class are to: <ul style="list-style-type: none"> <li>○ focus on Jenny's dilemma about getting tested for HD</li> <li>○ have students see what it's like to use an ethical decision-making model with reason and logic (not emotion) to arrive at a thoughtful course of action</li> <li>○ give students a tool for future ethical decisions they will face in later life</li> </ul> </li> </ul>
7	Read Part 3 Aloud	<ul style="list-style-type: none"> <li>• Coach distributes copies of <i>Family Secrets</i> Part 3 script to all students</li> <li>• Students are asked to listen and underline important facts as the scenario is read aloud.</li> <li>• Three students read aloud to class - Narrator, Jenny, and Dad</li> </ul>
5	Team Work Quick Brainstorm	<ul style="list-style-type: none"> <li>• Teams meet to briefly discuss major new Facts and/or Questions that arise from Part 3 script.</li> <li>• Coach may decide to get some whole class responses.</li> </ul>
25	<p>Ethical Decision-Making Process Model</p> <p>Steps 1-3</p> <p>Steps 4-6</p>	<ul style="list-style-type: none"> <li>• Coach hands out one <i>Ethical Decision-Making Process Model Worksheet</i>, to each student</li> <li>• Steps 1-3 are completed as a whole class discussion</li> <li>• Teams complete Steps 4-6 on <i>Ethical Decision-Making Process Model Worksheet</i>. Each student should have answers to these questions on their individual sheets.</li> <li>• Coach circulates among teams to monitor progress.</li> <li>• Individual sheets are collected and Team folders saved.</li> </ul>

Estimated Time (min.)	Summary Steps	Suggested Strategies
<b>Class 7</b>		
20	Ethical Decision-Making Process Model  Steps 7-8	<ul style="list-style-type: none"> <li>Coach distributes student folders and instructs students to complete Steps 7 and 8 on <i>Ethical Decision-Making Process Model Worksheet</i>. For Step 8, students write a position paper as described by their teacher.</li> <li>Coach collects completed <i>Ethical Decision-Making Process Model Worksheet</i> including each student's position statement.</li> </ul>
5	Modified Topical Barometer	<ul style="list-style-type: none"> <li>Coach tells students to write their name, the date on one Post-It and the number of the response that best answers the question "If they were Jenny, would they have the gene test done?" This time, students are given a forced choice, modified Topical Barometer with only two choices: 1-<i>definitely yes</i>, 5-<i>definitely no</i></li> <li>Students put up Post-It's on the "Modified Topical Barometer."</li> </ul>
5	Topical Barometers  Conclusions & Conversation	<ul style="list-style-type: none"> <li>Coach asks students to state conclusions from class results shown on the two Topical Barometers.</li> <li>Coach asks students to share their reasons if they changed their position on the topical barometer, or how they felt about only being given 2 choices this time.</li> </ul>
10	Position Statements or Practice Gel (if using pre-poured gels)	<ul style="list-style-type: none"> <li>Coach asks for volunteers who would read their position statements to the class. Call first for those who would have the test, then for those who would not have the test, then for ones who remain undecided.</li> </ul> <p><b>OR (if using one period version of Part 4 lab procedure)</b></p> <ul style="list-style-type: none"> <li>Students follow <i>Practice Gel Loading Instructions</i> to practice loading agarose gels. See Part 4.</li> </ul>
optional	Virtual Laboratory	<ul style="list-style-type: none"> <li>Coach shows or has students use <i>Part 2 of the Virtual Laboratory (Virtual Genetic Testing Procedure for Huntington's Disease)</i>.</li> </ul>
Homework		<ul style="list-style-type: none"> <li>Look at either the Dolan DNA Learning Center website <a href="http://www.ygyh.org/hd/whatisit.htm">http://www.ygyh.org/hd/whatisit.htm</a> or the DNAi website <a href="http://www.dnai.org">http://www.dnai.org</a></li> </ul>

## **Appendix A:**

### **Ethics, Bioethics and ELSI - Main Concepts**

#### **What is meant by “ethics” and “bioethics?”**

Ethics is the branch of philosophy that involves:

- deliberating about situations for which competing value systems offer different solutions
- identifying possible courses of action
- identifying supporting ethical principles and values
- choosing the most justifiable course of action

Bioethics is the field of ethics that deals with dilemmas and decision-making arising from advances and new technologies in biology and medicine. These fields include health care, the environment, reproductive technologies, biomedical and genetic engineering, and research into areas such as stem cells and genetic diseases and therapy.

#### **How is ethics different from “morality?”**

Morality is the term used to mean the accepted customs or social practices of a culture or groups within a culture. These customs or social practices usually have a basis in some authority such as religious training or parental upbringing, and are not generally the result of the kinds of deliberations found in the field of ethics.

#### **What is “ELSI” and why is it important?**

ELSI refers to the study and resolution of the Ethical, Legal, and Social Implications arising from scientific and medical advances. Advances in biomedicine and biomedical technology have changed the world and the everyday lives of its citizens. New drugs can now treat people whose conditions formerly caused death or severe impairment. Body parts can be replaced with mechanical parts or donated organs. Couples who were infertile are now able to have children. We can use genetic tests to predict whether or not a person is susceptible to develop a medical condition, and then use a variety of medical technologies to delay or prevent the onset of that condition. Because of advances such as these, people are living longer and better lives. With all of these benefits to individuals and society, however, has come a new set of risks, ethical issues, and problems. Questions arise which force us to make ethical, legal, and social decisions:

- Must we always use technology, or is it acceptable to just let nature “take its course?”
- How should we distribute our newfound knowledge and resources, and who should decide who gets what?
- What are the implications to individuals and society of knowing private medical information, such as results from genetic testing, and who should have access to that information?



## Ethical, Legal, and Social Implications of Genetic Technology Internet Resources

### Internet Resources for Students

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1. **Genetics Education Center**

Lists extensive (142) links to the following topics: HGP, genetic education resources, networking, genetic programs, activities and resources, writing about individuals with genetic conditions, and others.

<http://www.kumc.edu/gec/>

2. **Ethical, Legal, Social Implication of the HGP**

Identifies numerous links (number in parentheses) in the following areas: policy papers on specific issues and professional societies (6), Resources on ethics/legal issue/public policy (25), genetic testing/insurance/privacy/nondiscrimination (27), specific condition (including HD) (9), health insurance portability and accountability act of 1996 (4), and more.

University of Kansas Medical Center

<http://www.kumc.edu/gec/prof/geneelsi.html>

3. **Genetic Privacy and Legislation**

Excellent links to numerous other sites that summarizes privacy and legal issues in the following areas: federal genetic policy (including Clinton's executive order, congressional bills and upcoming hearing), state genetics policies (including NYS), existing federal antidiscrimination laws and how they apply to genetics, why legislation is needed, and cases of genetic discrimination

Human Genome Project

[http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/legilat.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legilat.shtml)

4. **Ethical, Legal, and Social Issues**

This DOE and NIH funded site for ELSI issue dissemination provides comprehensive links to "societal issues arising from the new genetics" as well as links for basic information about the HGP and medicine and the new genetics. ELSI links include area of privacy and confidentiality, gene testing, patenting, forensics, reproductive issues, psychological impact and stigmatization, and others.

Human Genome Project Information

[http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/elsi.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml)

5. **Bioethics Resources on the Web**

Internet links from the NIH about bioethics, general resources, federal resources, research ethics and medicine and health care.

National Institute of Health

<http://www.nih.gov/sigs/bioethics>

6. **Public Health Genomics**

Centers for Disease Control

<http://www.cdc.gov/genomics/>

**7. *Bioethics Information Center***

Loaded with links to topics such as bioethics on-air, bioethics and the law, genetics and ethics, religion and bioethics, and bioethics resources.

Buffalo Free Net

<http://www.bfn.org/~bioethic/>

**8. *Ethical, Legal and Social Implications (ELSI) Research Program***

Discusses and shows links to NHGRI goals, grant abstracts, funding opportunities, and research staff contact information.

National Human Genome Research Institute (NHGRI)

<http://www.genome.gov/10001618>

**9. *What is ELSI?***

Introduces basic questions arising from research and the need for a discussion on benefits of research and the need to educate on ELSI issues.

Lawrence Berkley National Laboratory

<http://www.lbl.gov/Education/ELSI/what-is-elsi.html>

**10. *Who Owns Your Genes? Rights and Wrongs***

Provides a brief discussion with questions about ethical issues concerning genetic information, including self-determination, privacy and confidentiality, right to work, right not to know, third party issues, and interests of employers and insurers.

BioNet

[http://www.bionetonline.org/English/content/gh\\_eth.htm](http://www.bionetonline.org/English/content/gh_eth.htm)

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**Internet Resources for Teachers**

**11. *What is Genethics?***

This article defines genethics, and gives a critical review of the book, Companion to Genethics, a collection of essays about the ELSI of genetic research.

Journal of Medical Ethics

<http://jme.bmjournals.com/cgi/content/full/30/3/326>

**12. *Basic Principles of Bioethics and Biolaw***

Outlines the current state of bioethics and biolaw from a European perspective, and provides another look at the principles of autonomy, dignity, integrity, and vulnerability.

University of Copenhagen

<http://www.bu.edu/wcp/Papers/Bioe/BioeRend.htm>

**13. *Genes and Justice***

Nine articles in the November-December, 1996 (Vol.83, No.3) publication are cited in other resources as background information on bioethics and the law. The three articles are entitled:

- Hope, Fear, and Genetics: Judicial Responses to Biotechnology
- Genes, Dreams, and Reality: The Promises and Risks of the New Genetics
- The Human Genome Project and the Courts: Gene Therapy and Beyond

American Judicature Society

[http://www.ornl.gov/sci/techresources/Human\\_Genome/publicat/judicature](http://www.ornl.gov/sci/techresources/Human_Genome/publicat/judicature)

**18. Genetic Testing and Screening in the Age of Genomics Medicine**

Long but easily-read and comprehensive report related to New York State law. Contains (skim-able) background information on genes, mutations, and disease, but continues with important topics such as HGP & health care, genetic testing, assessing accuracy of testing, predictive testing, misconceptions, genetic screening (adults, minors, newborns), financial considerations, informed consent, confidentiality, and recommendations of the task force.

NYS Task Force on Life and the Law: revised 2001 Executive Summary

<http://www.health.state.ny.us/nysdoh/taskfcr/screening.htm>

**19. Bioethics – An Introduction**

Introduction provides research-based objectives and reasons for teaching bioethics, a definition and model to introduce bioethics discussions into lesson plans, and provides a brief discussion of “pitfalls and possibilities” as well as a short list of benefits of teaching using this model.

Access Excellence / Woodrow Wilson Biology Institute

[http://www.accessexcellence.org/AE/AEPC/WWC/1992/bioethics\\_intro.html](http://www.accessexcellence.org/AE/AEPC/WWC/1992/bioethics_intro.html)

**20. Introduction to Types of Ethical Systems**

This article provides an excellent short overview and description of 5 ethical systems (relativism, divine command theory, utilitarianism, deontology, and virtual ethics). It provides scenario examples for student evaluation and an answer sheet for teacher that identifies which system is being depicted in each scenario.

Access Excellence / Woodrow Wilson Biology Institute

[http://www.accessexcellence.org/AE/AEPC/WWC/1992/ethical\\_systems.html](http://www.accessexcellence.org/AE/AEPC/WWC/1992/ethical_systems.html)

**21. Presenting Ethical Dilemmas in the Classroom**

This lesson plan is a tool for discussion of any bioethical topic. It provides teacher background information as well as hints for implementing the lesson plan. An 8-step ethical decision-making process is presented as part of the lesson.

Access Excellence / Woodrow Wilson Biology Institute

<http://www.accessexcellence.org/AE/AEPC/WWC/1992/dilemmas.php>

**22. A Process: Framework for Teaching Bioethics**

The paper provides a 7-step process for teaching bioethics by charting a practice profile that describes what the teacher and the students are doing in each of the steps. A narrative of each of the steps expands on the information in the practice profile. Morality, Ethics, and Values are defined, compared, and contrasted.

Teacher hints are given throughout the lesson.

Access Excellence / Woodrow Wilson Biology Institute

[http://www.accessexcellence.org/AE/AEPC/WWC/1992/teaching\\_bioethics.html](http://www.accessexcellence.org/AE/AEPC/WWC/1992/teaching_bioethics.html)

**23. Bioethics in the Classroom**

This short article lists 5 reasons for teaching bioethics in the classroom, 4 problems to consider, and 4 suggested steps to facilitate classroom discussion. References and additional links are provided for bioethics web resources, bibliography, and worksheets and links to the Hastings Center’s New Choices, New Responsibilities curriculum guide.

Access Excellence / Classrooms of the 21<sup>st</sup> Century

<http://www.accessexcellence.org/21st/TE/BE/>

**Appendix B: Ethics and Bioethics - Assessing Prior Knowledge**

***Family Secrets: Part 3***  
**Assessing Prior Knowledge**

**Team Members' Names:** \_\_\_\_\_

**Take 5 minutes to jot down some ideas that come to mind, either from your research so far in your teams, or from your personal background, when you hear the following terms: Ethics and Bioethics**

**Ethics:**

**Bioethics:**

## Appendix C: Major Ethical Principles Chart

Individual Rank	Ethical Principles	Example	Example
	Right to decide - <b>Autonomy</b>	Choosing a career or college that's different from one that your family or your friends recommend.	
	Doing what is best - <b>Beneficence</b>	Deciding to exercise on a regular basis.	
	Being fair - <b>Justice</b>	Deciding to give everyone on the team a chance to play.	
	Do no harm - <b>Nonmaleficence</b>	Deciding not to eat junk food that could be harmful for you?	

## Appendix C: Ethical Values Chart

### Rank only the top 3 Values

Rank	Values	Example	Example
	Relieving the other's suffering <b>(Compassion)</b>	Providing food for the hungry	
	Keeping a secret <b>(Confidentiality)</b>	Not telling others that a friend has cheated	
	Keeping a promise <b>(Fidelity)</b>	Remaining faithful to a spouse	
	Treating others as you would like to be treated <b>(Golden Rule)</b>	Holding the door open for an elderly person	
	Telling the truth <b>(Honesty)</b>	Admitting that you were speeding	
	Conforming to your principles/values <b>(Integrity)</b>	Not copying answers to the homework	
	Keeping from public view <b>(Privacy)</b>	Asking that a bank not release your financial information to others	
	Preserving the dignity of self and others <b>(Respect)</b>	Speaking without profanity or ethnic slurs	

## Appendix D: Bioethical Dilemma Word Splash Poster

### *Family Secrets: Part 3* Bioethical Dilemma Word Splash Poster

**Team Members' Names:** \_\_\_\_\_

**On the poster paper provided, list as many examples of ethical (bioethical) dilemmas that your team can think of in the time given. You may also list words, concepts, or ideas that come to mind as you list the examples.**

**Pick at least one ethical dilemma, and identify on the poster the competing ethical principles and/or value systems that make your choice an ethical dilemma.**