

# personal genetics education project

## **Social, Legal and Ethical Issues in Personal Genetics**

**Title:** Debating Ethical Questions about Genetics and Reproduction  
(Discussion scenarios and fishbowl debate)

**Aim:** How does genetic testing of embryos offer both hope and ethical dilemmas for parents?

**Time:** 1-2 days

### **Guiding Questions:**

- What are the ethical issues in using reproductive genetic testing?
- What are the possibilities and limits of using reproductive technologies to choose characteristics of children?
- Do we need rules for this type of biotechnology or not? If so, who should make the rules and with what authority?

### **Learning Objectives:**

After completing this lesson, students will be able to:

- Define pre-implantation genetic diagnosis (PGD)
- Discuss the risks and benefits of PGD
- Analyze the ethical dilemmas PGD brings to light
- Argue for or against the use of PGD and support their opinions with facts and examples

**Materials:** Projector or Smartboard, laptop, handouts (in lesson plan), chart paper, markers

### **Common Core Standards:**

RH.9-10.9. Compare and contrast treatments of the same topic in several primary and secondary sources.

RST.11-12.2. Determine the central ideas or conclusions of a text; summarize complex concepts, processes, or information presented in a text by paraphrasing them in simpler but still accurate terms.

RST.11-12.7. Integrate and evaluate multiple sources of information presented in diverse formats and media (e.g., quantitative data, video, multimedia) in order to address a question or solve a problem.

**Note to teachers and background information:** This lesson tackles a promising and controversial biotechnology – pre-implantation genetic diagnosis (PGD). PGD is a process in which a single cell is removed from an 8-cell embryo created by in-vitro fertilization (IVF) and tested for various genetic traits. Based on the results of the tests, one or more embryos can be selected for implantation into the woman’s womb.

PGD is often used to test for fatal childhood cancer and other fatal childhood diseases, many types of which run in families, with the goal of avoiding that specific disease.

In advance of this lesson, read [About Genetic Selection](#) (including the information from the Frequently Asked Questions link on the page) and for a more personal story, “[Couples Cull Embryos to Halt Heritage of Cancer](#)” by Amy Harmon in the *New York Times*.

A crucial point to make in a lesson about PGD is that many traits people might find appealing, whether it be perfect health or athletic prowess, are unlikely to be achieved via genetic selection. This is in part because single genes or discrete clusters of genes that are associated with complex social or physical traits may never be found or understood. For example, there is no one gene that is clearly and singularly linked to something like height, or the ability to swim long distances. These kinds of traits are likely the result of an inextricable mix of genes and environment, in the broadest sense of the word. The definitions of some traits, such as “beauty” or “intelligence” are fluid and subjective. How intelligent you are often depends on what test you are taking, and how “beautiful” you are depends on where and in what historical time you are living.

PGD is often discussed in the same breath as “designer babies” or as a modern form of eugenics. “Designer babies” is the term used to describe what some fear is the future of genetics and genomics: that parents will be able to choose any number of traits and characteristics in their children or alter existing genetic characteristics to be more desirable. It is important to make clear the distinction between PGD and the idea of “altering” embryos or inserting or deleting certain genes into an embryo (which doesn’t happen in PGD).

**Before the lesson – for students:** Have students read [About Genetic Selection](#) (including the information from the Frequently Asked Questions link on the page) and/or for a more personal story, “[Couples Cull Embryos to Halt Heritage of Cancer](#)” by Amy Harmon in the *New York Times* (both mentioned above). The *Times* article is quite long, but very informative and offers a personal story to which more students will relate.

**Activity:****Power Point slide show (10 minutes)**

We have a short slide show that gives students a brief overview of PGD. It helps define what the process is, and offers students an idea of what some of the social issues related to it are, particularly issues that are raised in the scenarios. You should rearrange or delete slides to best fit your class and students' needs. The slideshow is located on the website with the lesson.

The slideshow begins with two discussion questions, which should take a couple of minutes. It ends with discussion questions for the end of class, if you have time.

**Scenarios (35-45 min)** Students will read and discuss various scenarios related to PGD in order to understand a variety of the issues surrounding this technology. They will then share what they've learned with their classmates.

1. Break students into 5 groups, and give each group a different scenario (below).
2. Have each group read their scenario, either together or independently. Each scenario has 2-3 questions to answer. Students should discuss the answers to the questions, though they will need to answer individually, because several questions ask about their personal opinion.
3. Next, give each group a piece of chart paper and markers. They should summarize their scenario in 2-3 bullet points, to explain briefly to the rest of the class. They don't need to write the answers to the questions, since they will vary, but they should then discuss the questions/issues that were raised, and highlight some of their responses to the questions.
4. Have each group come up to briefly present their scenario and the main ideas raised. Be sure to help kids explain their opinions, and encourage other students to discuss if time allows.
5. If time permits, return to the discussion questions on the last slide of the slideshow.

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering questions individually on a separate piece of paper.

### **Scenario A: A family decides about genetic testing**

Imagine, in the next 10-15 years, a team of scientists discovers a series of genes linked to "intelligence." A test is developed that can be performed on embryos before they are implanted, and a company begins to sell the test to doctors.

You want to give your children every advantage possible. You've saved to buy a house in a town with good schools, sent your first child to dance class, language lessons, and soccer camp. The company that sells the test claims children who are selected for "intelligence traits" could go on to better colleges, earn more money, etc.

You are planning to have another child, and are debating whether to use this new PGD test to select an embryo with optimal intelligence. You used IVF for your first child because of fertility issues and expect you will use it again. Since you are already doing IVF, to add the PGD screening will cost between \$1000 - \$3000 and will not change the medical procedures that you are undergoing.

1. Do you trust this company's claim? Would you be able to discover how accurate this test really is? Why or why not?
2. How would you choose what you think of as "smart?" Is there only one way to be intelligent? Is it better to be good at math than writing? Does one ability make you smarter than another? Think about a famous artist like Picasso or Rembrandt; if you gave them a chemistry test, do you think they would still appear to be brilliant? Explain.
3. Is this fair to the oldest child? How would you feel if you were the older child, and your parents possibly think you're not as smart as your younger sibling and/or have lower expectations for you? Is this fair to the second child? Why or why not?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering questions individually on a separate piece of paper.

### **Scenario B: A family weighs their options to help a sick child**

PGD is usually used when a parent has a high likelihood of passing on a severe genetic disease to a child. It is used to allow doctors to implant embryos that are free from a particular genetic disease. Often the illness is an early-onset (childhood), fatal disease. Supporters of this technique argue that the child born after such a screening benefits because he or she is born without a fatal disease that runs in the family.

Some families do an additional type of testing on embryos, called HLA typing, to make sure that the embryo will grow to become a perfectly matched donor for a gravely ill older sibling. The idea is that this child would be a match to donate cells or tissues, or even an organ if needed (later in life), to her or his sibling.

In your family, you are planning to have a second child. Your first child is very sick and needs a transplant (of cells harvested from a second child's umbilical cord blood at birth in a painless, one-time procedure) to survive. There is no guarantee a transplant will permanently cure your sick older child, but, from the medical perspective, it is the best-known approach.

You are considering using PGD for HLA typing. PGD is being used to avoid the illness your first child has and to make sure a future child could also be a donor. The hope is that this child will be needed to donate only stem cells from the umbilical cord (painless for the baby). However, it is possible that this child may be called on to donate other tissues, such as bone marrow, sometime in the future.

This also means you would have to undergo in-vitro fertilization, which can cost up to \$15,000 per attempt.

1. What would you do as a parent if you were in this situation? Why?
2. How do you explain to both children (when they're older) the role the younger played in the life of the first child? How could this impact how each child sees his or her role in the family?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering questions individually on a separate piece of paper.

### **Scenario C: Congress is asked to vote on genetic testing of embryos**

You're a member of the US House of Representatives. Imagine that a bill has been brought forward to ban the procedure called PGD with HLA typing (note: this is a hypothetical situation). PGD/HLA is a combination of testing that tests embryos for a specific genetic mutation that may lead to disease, as well as testing the embryo's potential to be a perfect match for a sick sibling. If a second child is born, blood cells from his umbilical cord would be removed and transplanted into the sick child (this is done in a painless procedure after the baby's umbilical cord is cut).

The bill argues that it is not in the best interest of that child to be born as a perfectly matched donor due to the expectations of the parents and older sibling.

Opponents sometimes refer to these children as "made to order" because the child is at risk for being pressured to donate to a sibling and may not be able to fully agree to or understand the risks. They argue that children have a right to be born without this sort of agenda and burden and need to be protected from their well-intentioned parents. Parents, when faced with the possible or likely death of a child, cannot be trusted to fairly evaluate what's best for a child born in this manner.

However, some patient groups want PGD with HLA typing to be allowed without restrictions, leaving the choices between a doctor and patient. They argue that it is unethical to restrict a technology that can lead to healthier children and save the lives of children who are suffering. As there are proven successes with PGD/HLA, it is imperative to spare children and families of this suffering when at all possible.

1. Is it ethical to test embryos to find a match for a sick sibling? Why or why not?
2. How would you vote, if you were in Congress: to allow it to continue, or to ban it? Why?
3. Are there other options besides banning the procedure, or having no legal guidelines to guide the use of the technology? What might a compromise solution be?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering questions individually on a separate piece of paper.

**Scenario D: A family decides whether to have a baby with what is traditionally thought of as a genetic disorder or disability**

You and your partner are going to have a baby using in-vitro fertilization (IVF). You are both deaf, and proud members of the Deaf culture, with its own language and values. You have one child who is deaf. You hope your second baby will also be deaf, so he or she will be a part of your family's culture and community; you don't feel like deafness is a disability.

You have heard that some deaf people who have used IVF asked the doctors to test the embryos to see which ones have the genetic make up to be deaf and which would have the genetic profile to be hearing. You and the doctor can potentially choose which embryos to implant.

If you have a hearing child, she might be alienated from his or her own family, though the child would be less isolated in the larger world. If you have a deaf child, he or she will be a part of your family's culture, have your support in how to navigate the world as a deaf person, and be part of a small and close-knit deaf community. However, deaf people tend to have difficulties in school and finding a job, and can face social isolation.

Note a couple of important things to think about: First, this is a very rare scenario. Second, not all doctors will agree to purposefully help families choose embryos that will have what is considered a disability, because many doctors think genetic testing is to *prevent* genetic disorders. Also, when choosing the embryos to implant in a woman's uterus, the choice is not between *making* a child deaf or hearing; nobody is *manipulating* the embryo. The choice is between choosing an embryo that, from a genetic standpoint, is already likely to be deaf or to be hearing.

1. If you were the parent, would you choose the embryo(s) that will likely be deaf, or hearing? Why? What factors do you consider?
2. Who should get to decide if such approaches are ethical? The parents, doctors, lawmakers, or other outsiders (society)? Explain.

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering questions individually on a separate piece of paper.

**Scenario E:**

Huntington's disease (HD) is a disorder passed down through families in which nerve cells in certain parts of the brain waste away. It is caused by a genetic variant (also known as a mutation) in the Huntington gene on chromosome 4. Most people first develop symptoms in their 30s or 40s, and die about 15-20 years after symptoms develop. As the disease is passed down in families, symptoms develop at younger and younger ages. There is no cure for Huntington's.

Huntington's Disease is a devastating disease. Symptoms include behavioral disturbances, hallucinations, irritability, paranoia, and psychosis. Abnormal and unusual movements include facial movements, including grimaces, and quick, sudden, sometimes wild jerking movements of the arms, legs, face, and other body parts. Affected individuals suffer from dementia that slowly gets worse, including disorientation or confusion, loss of judgment and memory, and personality changes. Complications include: loss of ability to care for self, loss of ability to interact, injury to self or others, depression and death.

(adapted from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001775/>)

If one of your parents has Huntington's disease, you have a 50% chance of inheriting the HD variant. If you inherit it, you will develop the disease at some point in your life and can pass it on to your children. If not, you will not develop Huntington's disease and will not pass it onto your children.

It is possible for some people who know they have the HD variant to go through a process to avoid passing the affected gene to their children. By retrieving a woman's eggs for in-vitro fertilization (IVF) and fertilizing the eggs with sperm outside the womb, it is possible to test the embryos prior to implantation. Only embryos free from the variant associated with HD are selected for transfer into the mother's womb. If IVF is used for reasons other than infertility, it is usually not covered by insurance, and IVF with PGD costs around \$15,000.

1. If you knew that you carried the HD variant but wanted to have children, what are your options? What do you think you would do in this situation?

2. What do you see as the biggest risks and benefits in using this technology?

**Part 2 - Fishbowl Discussion:** If time allows (this portion of the lesson adds an additional day) students will participate in a fishbowl discussion about the use of PGD in order to dig deeper into the questions and discuss the ethics of this technology with their classmates. Students should read the articles at the beginning of the lesson and all of the scenarios from Day One to inform their opinions.

**Process:** A fishbowl discussion allows for multiple perspectives and opinions in a structured environment, and encourages (or requires) all students to participate. A detailed description on how to run a fishbowl discussion is at Facing History and Ourselves, <http://www.facinghistory.org/resources/strategies/fishbowl>. The “fishbowl” is a teaching strategy that helps students practice being contributors and listeners in a discussion. Students ask questions, present opinions, and share information when they sit in the “fishbowl” circle, while students on the outside of the circle listen carefully to the ideas presented and pay attention to process. The roles then reverse. This strategy is especially useful when you want to make sure all students participate in the discussion, when you want to help students reflect on what a “good discussion” looks like, and when you need a structure for discussing controversial or difficult topics.

A fishbowl requires a circle of chairs (“the fishbowl”) and enough room around the circle for the remaining students to observe what is happening in the “fishbowl.” Sometimes teachers place enough chairs for half of the students in the class to sit in the fishbowl, while other times teachers limit the chairs in the fishbowl. Typically six to twelve chairs allows for a range of perspectives while still allowing each student an opportunity to speak. The observing students often stand around the fishbowl.

There are many ways to structure a fishbowl discussion. Sometimes teachers have half the class sit in the fishbowl for 10-15 minutes and then say “switch,” at which point the listeners enter the fishbowl and the speakers become the audience. Another common fishbowl format is the “tap” system, where students on the outside of the fishbowl gently tap a student on the inside, indicating that they should switch roles. See the variations section for more ideas about how to structure this activity.

Regardless of the particular rules you establish, you want to make sure these are explained to students beforehand. You also want to provide instructions for the students in the audience. What should they be listening for? Should they be taking notes? Before beginning the fishbowl, you may wish to review guidelines for having a respectful conversation. Sometimes teachers ask audience members to pay attention to how these norms are followed by recording specific aspects of the discussion process such as

the number of interruptions, respectful or disrespectful language used, or speaking times (Who is speaking the most? The least?)

After the discussion, you can ask students to reflect on how they think the discussion went and what they learned from it. Students can also evaluate their participation as listeners and as participants. They could also provide suggestions for how to improve the quality of discussion in the future. These reflections can be in writing, or can be structured as a small or large group conversation.

**Assessment:**

1. In addition to participation, assess students through a 1-2 paragraph response to each set of questions posed at the end of the description of each scenario. Students will probably need to complete these questions at home.

## **Classroom tools:**

The accompanying PowerPoint slides are meant to organize the discussion and are easily modifiable.

## **For further reading:**

We are presenting a number of different perspectives on these subjects. Reproductive technology is often a heated, controversial topic and we are including a wide range of opinions. Inclusion does not constitute an endorsement.

[Genetic Dilemma's: Reproductive Technology, Parental Choices and Children's Future](#) - Dena Davis

[The Baby Business: How Money, Science, and Politics Drive the Commerce of Conception](#) - Debra Spar

[The mismeasure of man](#) – Stephen J. Gould

[My Sister's Keeper](#) – Jodi Picoult (fiction)

[GATTACA](#) – written and directed by Andrew Niccol

Genetics and Public Policy Center, [Reproductive Genetics Initiative](#)

Center for Genetics Society, [Assisted Reproduction](#) section

The Nash family story is discussed in "[Son conceived to Provide Blood Cells for Daughter](#)" by Denise Grady. Molly Nash needed a stem cell donor as part of her cancer treatment. These stem cells would be taken from a second child's umbilical cord, and healthy cells would be transferred into her bone marrow. Her parents conceived a second child via PGD, Adam, who is both free of the disease his sister has and is a perfect immunological match for Molly. An "immunological match" means they shared certain biological traits that would make it unlikely for Molly's immune system to reject the transplant from Adam. A more recent article is here: [Embryo genetic screening controversial - and successful](#) and a longer and more detailed article is here: [The Miracle of Molly](#) (useful for the teacher's information).