

# personal genetics education project

## Social, Legal and Ethical Issues in Personal Genetics

### 3. Genetics and reproduction: Ethical questions now and in the future

#### Introduction:

This lesson tackles one of the more promising and controversial biotechnologies – preimplantation 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 traits. Based on the results of the tests, certain embryos are selected for implantation into the woman's womb.

PGD is often used to test for fatal childhood cancers with the goal of avoiding that disease, but also is used for other purposes. It is an excellent topic around which to organize a bioethics lesson because it touches on personal and societal issues simultaneously, introduces a new scientific technology, and presents dilemmas that are multilayered and engaging.

In advance of this lesson, read [Genetic Testing of Embryos: Practices and Perspectives of US IVF clinics](#), and for a more personal story, "[Couples Cull Embryos to Halt Heritage of Cancer](#)" by Amy Harmon in the New York Times.

Depending on the maturity of the students, the Harmon article could serve as a handout/reading assignment. Appropriate for most students is a news article about a brother and sister who are part of one of a well-known family that used PGD. 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. Her parents conceived a second child via PGD, named Adam, who is both free of the disease his sister has and a perfect immunological match for Molly.

A crucial point to make in a lesson about PGD is that many traits people might find appealing in their child, whether it be perfect health or athletic prowess, are unlikely to be fully achieved via genetic selection. Single genes or discrete clusters of genes that are associated with complex social or physical traits may never be found or understood. There is no one gene that can be tested that is clearly and singularly linked to something like height,

or the ability to swim long distances. Those kinds of traits are likely 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.

Note: This lesson lends itself to a more focused discussion of genetic disease. In particular, PGD highlights the difference between single-cell mutations with high penetrance (eg, those associated with monogenetic disease such as Huntington’s and Cystic Fibrosis) versus multifactorial illnesses, such as heart disease, obesity, and certain types of cancer.

Multifactorial diseases generally are caused by a mix of genetic, environmental and lifestyle factors and are presently not well addressed by PGD technology.

### **Guiding Questions:**

Where should the line be drawn on using reproductive genetics to choose characteristics of children? Do we need rules for this or not? And who draws the line, and with what authority?

### **Learning Objectives:**

After completing this lesson, students will be able to:

Define PGD

Discuss the risks and benefits of PGD

List the ethical dilemmas PGD brings to light

Argue for and against the use of PGD and support their opinions with facts and examples

Articulate how genome sequencing might intersect with reproductive genetics

## **The Lesson:**

1. The lesson is a workshop/break out session. Students are asked to put themselves in someone else's shoes and come to a consensus about how and if PGD should be used.

In advance of the lesson, print and distribute, "[Couples Cull Embryos to Halt Heritage of Cancer](#)" by Amy Harmon or, "[Son conceived to Provide Blood Cells for Daughter](#)" by Denise Grady.

Explain the basic concepts and techniques of Preimplantation Genetic Diagnosis, with emphasis on its usefulness in a family where there is a strong history of a heritable disease that is caused by simple mutations in a single gene. Examples of such a disease would be Huntington's Disease or Cystic Fibrosis.

Introduce the idea that as genome sequencing becomes more widespread and affordable, it is likely that connections between specific genes and specific diseases will continue to be made at a rapid pace. The technology used in PGD – genetically testing a single cell – is a fairly adaptable one and could conceivably be used to conduct any of the 1500 (and growing) genetic tests currently available or even produce a full sequence.

2. Although the potential for PGD is enormous, most people are presently using the technique to avoid serious genetic disease in their children. Through the readings, students will have gained an appreciation of the multiple perspectives and complexities of PGD and will know what an amazing gift PGD can be for families. Engage students by asking them what are their major concerns? Is it abuse of this technology? Screening against traits that are not so much serious as inconvenient, e.g., nearsightedness or baldness? Is it that it is too expensive to be widely available to all who want it?

3. Divide the class into groups of (ideally) 5-6 students. Each group decides on a spokesperson. Distribute the "cases" and facilitate discussion. Handouts for students here, with an additional set of questions and notes for the teacher here

At the end of the allotted time (generally 10-20 minutes), ask each group leader to report on the issue that was discussed and describe what, if any, agreement the group may have been able to reach.

4. To bring the discussion to a close, refer to the final two slides that show for what PGD is most commonly used, and the overview of public attitudes on the use and regulation of PGD. Discuss with the class how their conclusions intersect with the general population reflected in the survey.

These slides often help students see the issues in a broader context and recognize that they have something to add to the debate. A wealth of resources are available at [www.dnapolicy.org](http://www.dnapolicy.org), and they update their website frequently.

### **Assessment:**

1. In addition to participation, assess students through a 1-2 paragraph response to each of the questions posed at the end of the description of their scenario. They should include a discussion of why or why not their group was able to come to a consensus.

Alternatively, each student could write a 1-2 page essay on their scenario, explaining at least 2 divergent viewpoints, and make a decision on where they stand.

2. PGD is often in the news, so there are many organizations and blogs that regularly write about PGD and other types of reproductive genetics technologies and associated ethical dilemmas.

Require students to post a comment (or several comments) on blogs such as [www.eyondna.com](http://www.eyondna.com) , [www.blog.bioethics.net](http://www.blog.bioethics.net), or [www.womensbioethicsblogspot.com](http://www.womensbioethicsblogspot.com). Commenting on an older post can be a worthwhile experience, especially since the authors will often respond directly to their commenters.

### **Classroom tools:**

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

## **More resources:**

### **News articles and blogs:**

Weekly [news round-up](#) from American Society of Reproductive Medicine

[Eye on DNA's coverage of PGD](#)

### **Books, articles, movies on biology, society, determinism, and eugenics**

A note of this following list: We are presenting a number of different perspectives on these subjects. It is often a heated, controversial topic and we are including a wide range of opinions. Inclusion does not constitute an endorsement.

[In the name of eugenics](#): Genetics and the uses of human heredity – Daniel Kelves

[The Unfit](#): The History of a Bad Idea – Elof Axel Carlson

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

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

[The Bell Curve](#) – Herrnstein and Murray

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

### **Organizations**

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

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

[American Society of Reproductive Medicine](#)