



## LESSON PLAN & TEACHER'S GUIDE

# Reproductive Genetic Testing:

## Technology, access, and decision making

### Aim

How does genetic testing of embryos and fetuses offer hope to individuals wishing to have children, and what are some of the ethical implications of that testing?

### Time

This lesson can be adjusted to fill 1 or 2 classes. It provides a selection of activities from which teachers can choose the most appropriate.

### Guiding questions

- Why have some people welcomed the option of genetic tests to learn about the genetic makeup of an embryo or fetus? What are the ethical issues surrounding the use of these tests?
- What are the possibilities and limits of genetic testing to choose characteristics of offspring?
- Are all of our traits determined by our genetic makeup?
- What are potential barriers for accessing reproductive genetic technologies?
- Do we need rules for the use of reproductive genetic technologies? If so, who should make the rules and how should they be enforced?

## Learning objectives

After completing this lesson, students will be able to:

- Discuss reproductive genetic testing technologies.
- Define non-invasive prenatal testing (NIPT) and preimplantation genetic diagnosis (PGD).
- Discuss the benefits of PGD and the ethical implications raised.
- Recognize the different viewpoints for and against the use of reproductive genetic technologies.
- Know that an individual's physical, mental and behavioral traits reflect environmental, lifestyle, as well as genetic influences.

## Materials

Projector or Smartboard, laptop, handouts.

## Standards alignment

### Common Core Standards

[CCSS.ELA-LITERACY.RH.9-10.9](#). Compare and contrast treatments of the same topic in several primary and secondary sources.

[CCSS.ELA-LITERACY.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.

[CCSS.ELA-LITERACY.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.

### Next Generation Science Standards

*This pgEd lesson integrates some of the NGSS practices and cross cutting concepts associated with the following disciplinary core ideas. The relevant portion of each disciplinary core idea is written out below.*

#### [HS-LS3: Inheritance and Variation of Traits](#)

*HS-LS3-1:*

- Ask questions to clarify relationships about the role of DNA and chromosomes in coding the instructions for characteristic traits passed from parents to offspring.

*HS-LS3-2:*

- Make and defend a claim based on evidence that inheritable genetic variation may result from: (1) new genetic combinations through meiosis, (2) viable errors occurring during replication, and/or (3) mutations caused by environmental factors.

## Background information

As the cost of genetic analysis decreases and as research advances, it is becoming increasingly possible to include a person's genetic makeup in the repertoire of tools that inform their health and well-being. Similarly, genetic analysis can be used in reproductive healthcare to learn about the DNA of an embryo in a Petri dish or a fetus in the womb, often as a way to gain medical insights at early stages of development. This lesson explores two such genetic technologies – preimplantation genetic diagnosis (PGD) and non-invasive prenatal testing (NIPT) – which allow people to screen embryos and fetuses, respectively, for a variety of characteristics. Students have the opportunity to explore the science, consider financial dimensions around access to new technologies, and examine ethical questions. This lesson encourages students to be informed, particularly as they will be taking charge of their own healthcare in a few short years and may be in a position to advocate for themselves and for others.

pgEd recognizes the wide diversity of perspectives that exist on these topics. This lesson does not ask students to choose a side, or even clarify their own views. It asks them to consider the complexities of new technologies and the information they can offer. In addition, pgEd strives to use gender neutral language in its materials. For example, in this lesson, the term “pregnant person” is used in recognition that not everyone who enters pregnancy would become a “mother” (e.g., in case of surrogacy) or identifies as a woman.

## Prenatal testing

Technology is transforming the ways that a person could learn about the genetic makeup of the fetus they are carrying. Previously, the only way doctors could analyze the DNA of a fetus was through an invasive procedure, either amniocentesis (typically at 15-20 weeks of pregnancy) or chorionic villus sampling (CVS; typically at 11-13 weeks of pregnancy). Since these invasive procedures involve collecting tissue or fluid from inside the womb, they both carry a small risk (how small remains a matter of debate, but could be anywhere from a .005% to 1% chance) of miscarriage. In 2011, a new generation of non-invasive prenatal tests (NIPT) became available for analyzing fetal DNA through a blood sample taken from a pregnant person's arm. NIPT can be performed as early as 9 weeks of pregnancy and, as with any blood test performed during pregnancy, NIPT does not increase the risk for miscarriage.

NIPT is most commonly used to screen for extra or missing copies of certain chromosomes, that can result in conditions such as Down Syndrome. NIPT can also assess the chromosomal sex of the fetus. This test is more accurate than previous generations of prenatal blood tests, which did not look directly at fetal DNA. Importantly, NIPT is not diagnostic. Because NIPT can be performed at an early stage of pregnancy and only requires a blood sample, it has been rapidly adopted by medical professionals and raises challenges around informed consent. As a result, people are grappling with how to handle genetic information about the developing fetus that is increasingly available to prospective parents. Ethical and practical questions abound about how this information might be used. These questions include (i) whether information learned via NIPT could improve medical care; (ii) how NIPT could impact pregnancy termination rates; and (iii) whether the availability of NIPT might add to the stigmatization of people with perceived disabilities.

### **Embryo testing**

Preimplantation genetic diagnosis (PGD) allows for the genetic diagnosis of embryos created by in vitro fertilization (IVF) - the fusion of egg and sperm in a lab. Based on the results of this analysis, one or more embryos can be selected for transfer into the womb. PGD can be used to assess whether an embryo has genetic variants that are associated with fatal diseases, such as Tay-Sachs disease and Huntington's Disease, with the goal of avoiding them. Since 1990, thousands of healthy children have been born in the US and elsewhere as a result of this technology, free of the genetic diseases that have, in many cases, devastated the older generations of their families. At the same time, PGD has raised ethical issues, as it gives individuals the capacity to select one embryo over another, and therefore brings to the forefront issues about autonomy, medical interventions, and disability.

### **Access to genetic technologies**

The costs of and access to genetic technologies is a rapidly changing landscape. In 2019, the cost of NIPT typically ranges between \$300 and \$8,000 US. This expense is widely covered by insurance companies for 'high risk' pregnancies (defined as women over the age of 35 or people with particular medical histories), and the trend in the US is moving toward coverage expanding to all pregnant persons.

The average cost of a combined IVF and PGD treatment in 2019 is \$20,000-30,000 US. In the US, sixteen states require insurance companies to cover or offer infertility-related treatment, but laws and rates vary. Only 9 of these states mandate coverage of IVF, and PGD is not covered by the majority of insurance companies. Many people pay for these treatments themselves without the help of insurance. Others who could benefit from these treatments are forced to go without, because the costs are prohibitive and insurance coverage is not consistent.

## A complicated conversation

People choose to use, or not use, NIPT and PGD for a multitude of reasons, and with very different religious, moral and ethical frameworks. Part of the challenge in teaching students about reproductive genetic technologies is that it can lead to discussion about one of the most contentious and difficult topics in the United States – the moral status of the embryo and fetus. Some people fear increased, earlier genetic testing edges close to the “slippery slope” of [eugenics](#); others see these tests as an important medical and decision-making tool. Providing students – who are also future health care consumers and possibly voters - with a venue to discuss complicated topics may require some additional supports. We recommend the guide “[Facilitating challenging conversations in the classroom](#)” from Washington University in St. Louis.

## Foundational concepts

It is key to convey to students that NIPT and PGD do not edit the DNA sequence of an embryo or a fetus, but instead assess the genes that are already present. The ability to directly edit the DNA sequence of human embryos is technically possible. It is currently illegal in the US, and fraught with ethical, religious, and safety concerns. In 2018, however, a scientist reported the birth of twin girls who had a section of their DNA edited while in the embryo stage. This was done using a genetic engineering technique called CRISPR, which caused permanent and heritable changes to the twin girls’ DNA. The scientific, ethical, and legal questions related to this story are covered in pgEd’s mini-lesson “[Claims of CRISPR being used to edit genomes of twin girls](#)”.

Another crucial point to make about genetic testing technologies is that many of the traits people might wish for in their children, such as (i) freedom from physical, mental, and behavioral disorders; (ii) athletic prowess; and (iii) mental agility, are unlikely to be achieved via genetic selection or genetic engineering. This is because our physical, mental and behavioral states are the result of complex interactions between multiple genes in combination with our environment and our lifestyles. Also, scientists are still far from having identified all the genes that contribute to our complex traits.

## Note to teachers

Through the readings and slides, students will gain a foundation to understand reproductive genetic testing technologies and their potential impacts on individuals and society. The classroom activity will allow students to explore complex scenarios surrounding reproductive genetic testing. This lesson gives students an opportunity to discuss many aspects of genetic testing, particularly PGD, such that they become aware of the diversity of opinions surrounding PGD. Because of the closely held, but often widely divergent viewpoints about genetic testing and reproductive matters, teachers may want to remind students of their classroom norms at the start of this lesson.

We have included a number of news articles and videos throughout this lesson plan. However, as technology evolves at a rapid pace, we recommend visiting <http://pged.org/genetics-and-reproduction/> for regular updates related to this lesson.

## Outline of resources and activities in this lesson

1. Part 1 – Student reading and 'Do Now' exercise ([page 7](#))
2. Part 2 – Slideshow (slide notes on [pages 8-14](#), questionnaire on [page 19](#))
3. Part 3 – Classroom activity ([page 15](#), discussion scenarios on [pages 20-24](#))
4. Part 4 – Fishbowl discussion ([pages 16-17](#))
5. Part 5 – Assessments & handouts ([page 18](#))
6. Short quiz (answer key on [page 18](#), handout on [page 25](#))
7. List of additional resources ([page 26](#))

## Activities

Do Now exercise (5-7 minutes), slideshow (20-25 minutes), scenarios (20-45 minutes), fishbowl discussion (20-30 minutes).

# Reproductive Genetic Testing: Technology, access, and decision making

## Part 1: OVERVIEW FOR STUDENTS

### Reading for students:

Before the lesson, have students read "[Couples Cull Embryos to Halt Heritage of Cancer](#)," by Amy Harmon in the *New York Times*. Although the article is long, it is very informative and offers a personal story to which students may relate. "[Chinese project probes the genetics of genius](#)" by Ed Yong in *Nature* will give students some background to tackle Scenario A, while reinforcing key concepts about genetic complexity.

### Do Now exercise (5-7 minutes):

Have students individually answer the following questions and then share their answers in a brief classroom discussion. These questions are on the second slide in the slideshow.

*If you could choose specific traits or qualities that you would want your child to have, what would you choose? Why?*

*Are there traits you would not want your child to have? What are they? Why?*

**Note:** An important concept to raise is that many physical, mental and behavioral traits are very difficult to predict or ensure. This is because such traits are the result of an individual's environment and lifestyle as well as an individual's genetic makeup. In addition, the genetic basis of many traits is extremely complex and beyond our current understanding.

# Reproductive Genetic Testing: Technology, access, and decision making

## Part 2: SLIDESHOW (20-25 minutes)

The PowerPoint slideshow introduces some major innovations in reproductive genetic technologies and the people and families impacted by these advances. We organized the slideshow to talk about NIPT first, as it is both new and increasingly common - and could be offered to many of your students during their lifetimes. After slide 6, we transition to PGD - a technique likely to be used by fewer people - but one that provides an excellent framework for an in-depth conversation about the issues related to genetic testing. It gives students a concrete understanding of the scientific concepts and offers an introduction to the social issues that are raised in the discussion scenarios ([pages 20-24](#)). These slides are intended to be flexible, so teachers may choose to modify them to best fit the classroom and student needs. The slideshow is located on the pgEd website along with this [lesson](#), and accompanying explanatory notes for the slideshow are provided below.

### Slide 2

**The questions for this “Do Now” activity will help students begin to consider the topics covered in the lesson.** Detailed notes for this slide are on [page 7](#).

### Slide 3

**This is an overview of how reproductive genetic technologies are used now, and might be used in the future.** The technologies presented are used to gain genetic information about embryos and fetuses, help people conceive, identify medical conditions that might be treated *in utero*, inform choices about embryo selection, and address heritable genetic diseases.

### Slide 4

**Amniocentesis and chorionic villus sampling (CVS) are common prenatal tests that are carried out to reveal information about the developing fetus.** Both are considered invasive procedures. An amniocentesis, typically performed between 15-20 weeks of pregnancy involves inserting a large needle through a pregnant person’s abdomen, uterus and then the amniotic sac to obtain fetal DNA from the amniotic fluid. CVS, typically offered at 11-13 weeks of pregnancy, is performed vaginally or via a needle through the abdomen to collect fetal tissue from the placenta. Both procedures carry a small risk (how small remains a matter of debate, but could be anywhere from a .005% to 1% chance) of miscarriage.



## Slide 5

**Non-invasive prenatal testing (NIPT) is a test that is used to understand the genetic makeup of a developing fetus.** NIPT has been available for clinical use in the US since 2011. The technique is most commonly used to look for extra or missing copies of certain chromosomes (a condition known as “aneuploidy”). One of the most common of these conditions is Down syndrome, which is characterized by having three copies of chromosome 21 in the fetal cells.

It is important to note that NIPT results are not definitively diagnostic. NIPT results may suggest the presence of aneuploidy, but more invasive forms of prenatal testing (see slide 4) are needed for definitive diagnosis. Similarly, one could receive an NIPT result that suggests a chromosomal condition is less likely, but it cannot completely rule them out. The likelihood that a positive NIPT result is truly positive varies for different conditions and for individuals of different age groups.

## Slide 6

**NIPT is “non-invasive” and allows for an analysis of fetal DNA at an early stage of pregnancy.** All of us have small fragments of DNA circulating in our bloodstream that are released from cells in our body. These fragments are known as “cell-free DNA”. During pregnancy, a small fraction of this cell-free DNA originates from cells of the placenta. The placenta is an organ formed by embryonic cells that connects the developing embryo (and later fetus) to the uterus and facilitates the exchange of gases, nutrients, and waste products. By obtaining a blood sample from the arm of the pregnant person, physicians and researchers can analyze these cell-free DNA fragments to reveal information about the developing fetus. NIPT can be performed as early as week 9 of the pregnancy. Because NIPT is done on a blood sample taken from a vein, it is considered a non-invasive procedure that does not, by itself, increase the risk of miscarriage. To read more about NIPT, see “[10 Breakthrough Technologies 2013: Prenatal DNA Sequencing](#),” by Antonio Regalado, May 2013, *MIT Technology Review*.

In rare cases, NIPT has detected cancer in the pregnant person. This often unanticipated result presents challenges for education, counseling and the consent process. Generally, a prenatal test is intended to reveal information about the fetus and not the health status of the pregnant person. The rapid adoption of NIPT will mean medical professionals will need to develop guidelines for these unexpected dimensions of NIPT.

## Slide 7

**In vitro fertilization (IVF) is a process used to help people with fertility issues.** In the IVF process, hormone injections are administered to stimulate the ovaries to produce mature eggs. These eggs are fertilized in a lab by the addition of sperm in a petri dish. One or more of the resulting embryos are then transferred to the uterus. IVF was first performed in 1978, and is estimated to account for 1-2% of US births annually.

## Slide 8

**Preimplantation genetic diagnosis (PGD) can be used to screen embryos during IVF to make a decision about which embryos to implant.** PGD gives people who carry variants for serious genetic diseases the opportunity to prevent passing these on to their offspring. Such genetic disorders include deadly childhood diseases, such as Tay-Sachs, as well as adult-onset diseases, such as Huntington's disease and certain inherited forms of breast cancer. Typically, a single cell is removed from an 8-cell embryo and screened for specific disease-causing variants. Any embryo that is free of the particular variant is then considered for transfer into the uterus.

Preimplantation Genetic Testing (PGT) is the new, umbrella term for the different types of preimplantation genetic tests that are available. We use the term 'PGD' throughout this lesson, as it is the type of preimplantation genetic testing that we are mainly focusing on and, moreover, it is the nomenclature used by the data that we cite. Different acronyms related to PGT are defined below:

1. PGD (D = diagnostic) → to test for specific inherited traits (e.g. cystic fibrosis or Huntington's disease)
2. PGS (S = screening) → to assess whether embryos have the typical amount of genetic material (i.e. no missing/extra chromosomes)

With the advancement of technologies, a [new nomenclature](#) has been suggested:

1. PGT-A (A = aneuploidy) → new name for PGS
2. PGT-M (M = monogenic) → to test for specific inherited traits controlled by a single gene (such as cystic fibrosis and Huntington disease)
3. PGT-SR (SR = structural rearrangement) → to screen for specific inherited chromosome abnormalities, such as translocations.

## Slide 9

**This slide shows an image of a cell being removed from an IVF-created 8-cell embryo (3 days after fertilization) for PGD.**

## Slide 10

**Genetic testing to select embryos for certain traits was brought into the public eye by the Nash family.** Pictured are siblings Molly and Adam Nash. Molly was born in 1994 with a deadly disorder called Fanconi Anemia (FA), a genetic condition that disrupts the ability of cells to repair their DNA and often leads to specific types of cancer like leukemia. As a young child, Molly needed a stem cell transplant to save her life. Her parents wanted another baby and decided to use PGD with the goal of conceiving a child who would be free from FA and a perfect donor match for Molly. When Adam was born in 2000, stem cells from his umbilical cord were transplanted in to Molly's bone marrow. Since the transplant, Molly has recovered, and both children are doing well.

The Nash family was one of the first in the United States to go public with their use of PGD for donor matching. While many people were supportive, the Nashes also faced criticism that Adam was a "designer baby" and suffered unjust risks, conceived only to help his sister. ['Little Frankenstein' conceived so Minnesota doctors could save sister, is now a happy teen,](#) *Star Tribune*, and video from ABC news, ["Nash family opens up."](#)

### Questionnaire activity

We recommend that you pause after slide 10 and conduct the following exercise, which encourages students to explore different opinions about PGD. Afterwards, students will see the results of studies that were designed to reveal what citizens of the United States think about PGD in Slides 11-13. Hand out the questionnaire on [page 19](#) of this document.

1. Tell the students NOT to put their name or any identifying mark on the page.
2. Have them answer the questions on their own.
3. Collect all the sheets, scramble and then redistribute them among the students at random.
4. Tell the students not to let anyone know if they happen to have received their own answer sheet back.
5. Ask the students to go through the sheet in front of them and think about how these answers may differ or overlap with their own answers. Discuss with the group if time allows, and then complete the slideshow.

## Slide 11

### **IVF clinics that provide PGD use this technology to test for a number of traits, ranging from serious genetic disorders to non-medical sex selection.**

This graph lets teachers reinforce some biology concepts, in addition to highlighting the range of applications of PGD, which include several that are not about avoiding medical conditions.

In a 2008 US-based study of 137 clinics, 42% of clinics surveyed offer to assess the sex of the embryo for “non-medical reasons.” For example, parents want a boy or a girl based on preference and not because they wish to avoid a genetic condition that is typically associated with one sex or the other. The study also shows that 3% of clinics allow families to select embryos with traits that others might see as a disability, such as deafness or dwarfism. The topic of PGD and deafness is explored in Scenario D of this lesson. Note: some of the percentages mentioned above have likely changed since their publication in 2008. Only one of these measures have been updated since 2008, and we included an update from 2018 showing that 72.7% of clinics now offer PGD for sex selection.

## Slide 12

### **The US public holds a range of opinions about the uses and limits of embryo testing via PGD.**

In a 2013 study, published in 2015, a majority of the 1006 Americans surveyed thought it was acceptable to use PGD to select embryos in order to avoid serious illness or disability, or to identify a match for stem cell donation. Note that close to 20% of people stated it would be acceptable to screen for personality traits and other complex characteristics, which are poorly understood and not suited to this sort of technology. These results provide the basis for a discussion to ensure students understand that it is difficult to discover the genetic contributions to traits as complicated as personality, intelligence, sexual orientation, and strength. Another important point to make to students is that people could see this survey and feel a sense of marginalization, because of worries that some of their traits are undervalued by others and could be erased. Additionally, even in a small study of 1006 people that may not include all voices, we can observe just how wide a range of views are expressed.

## Slide 13

**Opinions are divided on the need for government regulation of PGD.** Currently, there is little US government regulation of what embryonic and fetal traits can be examined via genetic technologies. The government regulates drugs, medical equipment, and the licensing of practitioners, which are all required to perform the described technologies. However, the genetic testing procedures themselves, such as

PGD, are not regulated by the federal government. The American Society for Reproductive Medicine issues guidelines, but they do not sanction any violations of their guidelines.

In this study highlighted on the slide, published in 2006, 62% of people surveyed thought there should be some government regulation. Another 17% believed the government should have no role in regulating PGD and that the patient or doctor can make any decision related to the embryos. Teachers can use this slide to emphasize the range of opinions illustrated, which may or may not also reflect the diversity of views in their classroom.

## Slide 14

### **Access to and cost of genetic technologies varies widely.**

**NIPT:** In 2019, the price of NIPT ranges between \$300-\$8,000 US. This cost is often covered for 'high risk' pregnancies (defined as women over the age of 35 or people with particular medical histories). Furthermore, it is increasingly covered by insurance companies for all pregnancies, as more doctors are recommending the test for their patients.

**IVF (required for PGD):** The average cost of IVF is \$10,000-15,000 US, a cost that many people cannot afford. Sixteen US states require health insurance companies to either cover or offer infertility-related treatments, the specifics of which vary highly from state-to-state. These state laws do not apply to public health programs such as Medicaid, which provides health insurance to low-income families. Only 9 of those 16 states mandate coverage of IVF, many of which award exemptions to small business or on the basis of religious grounds. Many insurance companies cover IVF only for married heterosexual couples, excluding the use of donated gametes and denying access to IVF for single parents and same sex couples. The variation of the rules and regulations state-by-state and for different contexts makes it

The reasons why insurance companies generally do not cover IVF and/or PGD are centered around cost. Some people are concerned that these procedures benefit a relatively small number of people, but costs are shared across the whole network in the form of higher premiums, and that coverage could increase the number of high risk, complicated, expensive pregnancies and births. However, proponents of insurance coverage for IVF and PGD argue that the initial costs will be less than the medical costs associated with supporting a lifetime of treatment for a genetic disorder: "[A Qualitative Inquiry of the Financial Concerns of Couples Opting to Use Preimplantation Genetic Diagnosis to Prevent the Transmission of Known Genetic Disorders](#)," by Kathryn T. Drazba, Michele A. Kelley, and Patricia E. Hershberger, August 2013, *Journal of Genetic Counseling*.

challenging for individuals to determine their insurance coverage, creating additional barriers for those who do not have the resources to do the research.

**PGD:** The average cost of IVF with PGD is \$20,000-30,000 US. In the United States, PGD is not covered under the majority of public and private health care companies. Moreover, individuals who pursue PGD often do not have infertility problems, and would not otherwise be seeking IVF to become pregnant. Therefore, under many coverage guidelines, the costs for the required IVF treatment are also not covered.

## Slide 15

**Discussion questions.** This slide provides some additional questions to promote discussion. Most importantly, students should come away knowing that there are many differing opinions about the use of genetic testing technologies. Teachers could also opt to use these for an in-class writing assignment or for homework.

## Reproductive Genetic Testing: Technology, access, and decision making

### Part 3: CLASSROOM ACTIVITY (20-45 minutes)

Students will read and discuss various scenarios related to PGD, provided on [pages 20-24](#) of this document, in order to better understand the issues surrounding this technology. These are typically used after the slideshow.

1. Break students into groups and give each group one of the five scenarios. Although not essential, we recommend giving each group its own scenario. One of the primary goals of this activity is to give students the experience of working with data and facts to inform different perspectives on genetic testing technologies. This activity also will help students become aware of the diversity of opinions and how to respect that diversity.
2. Within each group, have students read the assigned scenario and consider the accompanying questions.
3. Have students in each group present their scenario and the main ideas raised. Students may find it useful to refer to the articles they have read or examples in this lesson.

## Reproductive Genetic Testing: Technology, access, and decision making

### Part 4: FISHBOWL DISCUSSION (20-30 minutes)

If time allows, students can participate in a fishbowl discussion about the use of PGD. They will be encouraged to dig deeper into the questions and discuss the ethics of this technology. Students should read the articles at the beginning of the lesson ([page 7](#)) and all of the scenarios ([pages 20-24](#)) 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 description of the fishbowl technique 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 all students to participate in the discussion, to help students reflect on what a “good discussion” looks like and when you need a structure for discussing controversial 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 number of 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, in which students on the outside of the fishbowl gently tap a student on the inside, indicating that they should switch roles.

Regardless of the particular rules you establish, you should make sure they are explained to students beforehand. You also need 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 ( [“Facilitating challenging conversations in the classroom”](#) from Washington University in St. Louis is one resource). 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 (i.e. who is speaking the most? the least?)

After the discussion, you can ask students to reflect on how they think the discussion went, what they learned from it and how they evaluate their participation as listeners and as participants. These reflections can be in writing or can be structured as a small or large group conversation.

## Reproductive Genetic Testing: Technology, access, and decision making

### Part 5: ASSESSMENTS & HANDOUTS

#### Homework assignment:

In addition to participation, assess students through a 1-2 paragraph response to each set of questions posed at the end of each scenario ([pages 20-24](#) of this document).

#### “Reproductive Genetic Testing: technology, access, and decision making” quiz answer key

(see [page 25](#) for quiz)

1. Gain information about a fetus, help individuals conceive, allow individuals to select embryos based on the genetic makeup of the embryos.
2. D
3. F
4. T
5. F
6. A
7. F

# Reproductive Genetic Testing: Technology, access, and decision making

## STUDENT HANDOUT

### Questionnaire Activity

- Do ***not*** give your name or make identifying marks.
- Answer the following questions by circling Yes or No
- Note: I will not be saving these after the exercise.

Should people be allowed to test embryos...:

1. for painful, deadly diseases that develop within the first three years of life?  
Yes or No
2. for painful, deadly diseases that develop in young adulthood?  
Yes or No
3. for painful, deadly diseases that develop at age 75 or beyond?  
Yes or No
4. for diseases that are not usually deadly, but can have a major impact on the family?  
Yes or No
5. to choose the sex of the child?  
Yes or No

## Classroom activity Scenarios

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering the questions.

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

**Note:** *The genetics of intelligence is a very controversial topic. Not only is intelligence likely to reflect much more than just genetics, the mere definition of 'intelligence' is controversial. Perhaps for these very reasons, this is a useful example for illustrating the complexities of using genetic information.*

Imagine that, in the next 10-15 years, scientists discover a series of genes linked to intelligence. A test is developed that can be performed on embryos before they are implanted in the uterus, and a company begins to sell the test to doctors. The company that sells the test claims children who are selected for intelligence could go on to better colleges, better jobs, etc.

You want to give your children every advantage possible. You moved to be closer to the best school in your neighborhood and you spend as much time as possible helping with homework. Your child knows how important it is to work hard at school.

You used IVF for your first child because of fertility issues and expect you will use it again. You are now debating whether to use this new PGD test to select an embryo.

1. Should parents be allowed to test embryos for intelligence? Why or why not? Is it acceptable for a company to sell a test that says it can help parents choose a smart child? Explain.
2. If you were the parent, how would you define intelligence? Is there only one way to be intelligent? Is it better to be good at math rather than writing, for example? Does having certain abilities make you smarter than having others? Think about a famous artist, such as Pablo Picasso or Frida Kahlo; if you gave them a chemistry test, do you think they would still appear to be brilliant? Explain.
3. Are you being fair to the oldest child? How would you feel if you were the older child, and your parent thinks you are not as smart as your younger sibling? How would you feel if your parent had lower expectations for you? Is this fair to the second child?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering the questions.

**Scenario B: A family weighs its options to help a sick child.**

PGD can be used when a parent has a high likelihood of passing on a severe genetic disease. It allows doctors to implant embryos that do not carry the disease-causing genetic variant. Supporters of this technique argue that the resulting child benefits because they are born without the variant that causes this disease.

PGD also can be used to select an embryo that will grow to become a perfectly matched donor for a sick older sibling. The idea is that this child would be a match to donate cells, tissues or even an organ to their sibling.

Your first child is very sick and needs a bone marrow transplant. You are planning to have a second child, and, if that child were a match, it would be possible to transplant cells taken from the umbilical cord blood at birth. Blood is collected after the cord is cut and no longer attached to the baby. There is no guarantee that a transplant will permanently cure your sick older child, but, from a medical perspective, it is a good approach.

You are considering doing PGD both 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 only need to donate stem cells from the umbilical cord, which would be painless for the baby. However, it is possible that, sometime in the future, this child may be called on to donate other tissues, such as bone marrow.

1. What would you do as a parent if you were in this situation? Why?
2. How would you explain to both children the role that the younger sibling played in the life of the first child? How could this impact how each child sees their role in the family?
3. Discuss the ethical implications of choosing an embryo that will become a child who is a perfect match for an older sibling? Do you think it is ethical to let a child die without doing everything possible to save them? Explain.

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering the questions.

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

PGD can assess embryos for a specific genetic variant that may lead to a disease. It can also test the embryo's potential to be a perfect match to donate stem cells to a sick sibling. If a second child is born a match, blood cells from his or her umbilical cord would be removed via a painless procedure after the baby's umbilical cord is cut and transplanted into the sick child.

You are a member of the United States House of Representatives. Imagine that a bill has been proposed to ban some uses of PGD. The bill argues that it is not in the best interest of a child to have been selected as a perfectly matched donor for an older sibling.

Supporters of the ban argue that children who are a perfect match to an older sibling may be pressured to donate additional tissues or organs to that sibling. As children, they may not be able to fully understand the medical and emotional risks of becoming a donor, and they have a right to be born without this sort of burden. Supporters of the ban also are concerned that parents, when faced with the possible or likely death of a child, may have difficulty evaluating what is best for each child.

However, some patient groups want the use of PGD to be unregulated. 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.

1. Do you think it is 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: allow this use of PGD to continue or ban it? Why?
3. Currently, there are no federal laws in the United States governing how this technology should be used. Do you think there should be? Are there other options besides banning PGD or leaving PGD unregulated? What might be a compromise solution?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering the questions.

**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 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 more readily be a part of your culture and community; you don't feel like deafness is a disability.

You and your partner are hoping to have a baby using in vitro fertilization (IVF). You know some deaf people who have used IVF and PGD to determine which embryos have a genetic makeup associated with deafness and which have a genetic makeup associated with hearing. You have the potential to choose which embryos to transfer to the uterus.

If you have a child who can hear, they might be alienated from your family, though the child would be less isolated in the larger world. If you have a deaf child, they may more easily integrate into your family's culture, have your support in how to navigate the world as a deaf person and be part of a close-knit deaf community. However, deaf people often have a difficult time in school and in finding a job, and can face social isolation.

**Note:** First, the details of this scenario are not as important as the issues raised, which extend beyond this example and shed light on different perspectives on disability. Second, when choosing the embryos to transfer to the uterus, the choice is not between *making* a child deaf or permitting it to hear; ***nobody is changing or manipulating the embryo.*** The choice is between an embryo that, from a genetic standpoint, is already likely to develop into a child who is deaf or an embryo that is already likely to develop into a child who can hear.

1. If you were the parent, would you choose the embryo(s) that would develop into a child who would likely be deaf? Why? What factors would you consider as you make your decision?

2. There are debates about whether PGD should be used to select for traits traditionally considered a disability. Who do you think should decide how PGD is used: parents, doctors, lawmakers, religious leaders or others?

Name \_\_\_\_\_

Date \_\_\_\_\_

Directions: Read the following scenario and discuss the issues before answering the questions.

### **Scenario E: Using PGD when Huntington's disease runs in the family**

Huntington's disease (HD) is a genetic disorder in which nerve cells in certain parts of the brain waste away. It is caused by a variant in the Huntingtin gene. Most people affected by this disease develop symptoms in their 30s or 40s and die about 15-20 years later. As the disease is passed down from one generation to the next, symptoms develop at younger and younger ages. There is currently no cure for HD.

HD is a devastating disease. Symptoms include behavioral disturbances, hallucinations, irritability, paranoia, psychosis and loss of motor control. Abnormal and unusual movements include grimaces and wild jerking of the arms, legs, face as well as other body parts. Affected individuals also suffer from personality changes and dementia, including disorientation, confusion and loss of judgment and memory.

If one of your parents has HD, you have a 50% chance of inheriting the disease-causing variant in the Huntingtin gene. If you do inherit this, you will develop the disease at some point in your life, and each of your children will have a 50% chance of inheriting it from you. If you do not inherit this variant, you will not develop HD and will not pass it on to your children.

It is possible for people who know they carry a disease-causing genetic variant for HD to avoid passing it to their children. By using in vitro fertilization (IVF), in which eggs are fertilized with sperm outside the womb, it is possible to test the Huntingtin gene prior to transfer to the uterus. This strategy enables parents to select only embryos that are free from the disease-causing variant for HD.

1. If you knew that you carried a disease-causing variant in the Huntingtin gene 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 benefits and risks in using this technology?



## Reproductive Genetic Testing: Technology, access, and decision making

### QUIZ

Name \_\_\_\_\_

Date \_\_\_\_\_

1. Short answer: What are three purposes of reproductive genetic testing technologies?
2. Non-invasive prenatal testing (NIPT) is a type of reproductive genetic testing that:
  - a) requires a blood sample that is taken from the pregnant person's arm.
  - b) can provide information about the genetic make-up of the fetus.
  - c) might give information that is unclear or unexpected.
  - d) all of the above
3. The United States population agrees how and why genetic testing technologies technology should be used for all people. T/F
4. It is possible to use genetic testing to find out if a fetus is likely to develop into a child who has a condition such as Down Syndrome or has a higher risk than average for hereditary breast cancer. T/F
5. It is possible to use genetic testing to conclusively find out if a fetus will develop into a child who will be tall, good at math or a talented artist. T/F
6. Preimplantation genetic diagnosis (PGD) is a type of genetic testing that allows:
  - a) potential parents to test embryos for certain traits, usually to avoid serious medical conditions.
  - b) potential parents to choose traits like intelligence and height in their children.
  - c) children to learn about their own DNA when they turn 18.
  - d) allows potential parents to add desirable genes or delete undesirable ones from an embryo.
7. The United States highly regulates and monitors how reproductive genetic testing technologies are used. T/F

## Reproductive Genetic Testing: Technology, access, and decision making

### ADDITIONAL RESOURCES FOR TEACHERS

Information about [Assisted Reproductive Technology](#), from the US Centers for Disease Control and Prevention.

[“Pregnancy: Prepare for unexpected prenatal test results,”](#) by Diana Bianchi, June 2015, *Nature*.

[“Prenatal testing is about to make being pregnant a lot more stressful,”](#) by Kat McGowan, March 2016, *Quartz*.

[“A safe prenatal genetic test is gaining popularity with young moms-to-be and their doctors,”](#) by Sarah Elizabeth Richards, January 2019, *Washington Post*

[“A deep dive into newborns’ DNA can reveal potential disease risks — but is the testing worth it?”](#) by Andrew Joseph, January 2019, Stat News.

The Nash family story is discussed in [“Son conceived to provide blood cells for daughter”](#) in October 2000 by Denise Grady in the *New York Times* and [“Embryo genetic screening controversial - and successful”](#) in January 2010 by Dan Vergano in *USA Today*. For a longer and more detailed article about Molly Nash, read [“The Miracle of Molly”](#) in August 2005 by Amanda Faison in *5280: The Denver Magazine*. Also see the 2017 story by Jeremy Olsen, [“Little Frankenstein’ conceived so Minnesota doctors could save sister, is now a happy teen,”](#) *Star Tribune*, and video from ABC news, [“Nash family opens up.”](#)

[“Is it wrong to select a deaf embryo?”](#) March 2008, by Clare Murphy, *BBC*.

[“Scientists can design ‘Better babies’. Should they?”](#) by Clyde Haberman, June 2018, *New York Times*.

[“Why making a ‘designer baby’ is easier said than done”](#), by Richard Harris, May 2019, *National Public Radio*.