

Teacher notes/additional questions to stimulate discussion on genome sequencing and reproductive technology (pgEd's lesson 3).

### **Scenario A (family, testing for intelligence)**

What might friends and neighbors (none of whom have the means or desire to select for these sort of traits) have to say? What might they fear? eg, unfair competition in the classroom and on the playing fields...?

Do the issues change if the cost is covered by either private or government health insurance? Does universal access eliminate some of the concerns?

Fears about altering humans in ways that can't be reversed, "playing God", that children won't be happy or somehow suffer from parent's decisions, etc.

How likely it is that intelligence, or athleticism, is linked to a single, well defined gene or set of genes? No data to the effect exists at the moment, but students may be under the impression that there is..

Note: Discussion at this point may lend itself to talking about biological determinism, eugenics, and why as a culture we often are seeking biological answers to disparities that are likely more social, cultural, and economic in nature. See "Extending the Lesson" for additional readings.

### **Scenario B (Congress deciding to regulate genetic testing for certain traits)**

Encourage students to question the feasibility for testing for complex social traits such as intelligence or athletic skills.

Should the government have a hand in this, or should it be left for private individuals and their doctors?

Middle ground or other ideas: Some have proposed a non-partisan, new federal regulatory body to study and make policy about human biotechnologies. For more, see Francis Fukuyama and Franco Furger's [proposal](#) at The Hastings Center, a bioethics think tank . The UK has a

regulatory body that serves this function called the [Human Fertilisation and Embryology Authority](#)

Should it be put to a popular vote? Or be left to the states. Stem cell initiatives and regulations may be instructive in this case..

### **Scenario C (family, deciding about PGD/HLA)**

This procedure may be a huge financial burden. If it were covered by insurance, does that solve some of the dilemma?

Parents have children for all kinds of motives. Is having a child to save the life of another right? Does motive really matter, and who should judge?

What if the "savior" sib is asked to donate more than just the umbilical stem cells, like marrow or a kidney? In what ways might that possibility limit the child's choices in terms of travel, career, etc. Feelings of resentment, hostility towards the ill sibling, parents, etc.

Note: In the UK - this is a real ~~ly~~ issue. They have a federal agency called [HFEA](#) that looks into these questions of motive within a family before allowing them to proceed with PGD (it is government controlled and funded in the UK). Is that something that might work in the US?

### **Scenario D (Congress asked to ban PGD/HLA to protect "savior" sibs from exploitation)**

Does the scenario in which PGD/HLA is affordable for anyone who wants it change the debate?

Is the pro/con argument too black and white for this issue? Where are the issues that are gray?

What are some ways the child born via PGD/HLA might feel good about their role? Keeping sib alive, "savior" to his whole family, altruism? How freely chosen is that altruism?

**The following can be used for group discussion, homework essays, or exam questions:**

Big picture question: When thinking about new biotechnologies, who benefits? Who bears the burden?

1. Does PGD impose the values of one generation onto the next? What if what one generation's values are different from the next? Can you think of any examples?

2. Do you think there could come a time when having a child with physical imperfections or challenges, or genetic abnormalities will be seen as irresponsible? Why or why not?

3. How do you think public opinion and fears about disability impacts the use of PGD? What do you think disability-rights activists, or families with disabled members might feel about PGD?

4. Parents put a lot of time, energy, money, and love into giving their children every advantage they can. What is so different about trying to give them a genetic advantage? Should society have a say in such matters or is it a personal, family decision?

5. PGD is very expensive, adding an additional \$3000-6000 dollars onto an IVF cycle that costs on average \$12,400. Presently in the US, wealthier people are more able to use this technology. Is that fair? Is it important to make this accessible to anyone who wants it or not?

6. Some couples have used PGD to [select an embryo with a disability](#) - deafness. Also, parents with dwarfism have chosen to have a dwarf child via PGD. Many people who are deaf do not see themselves as disabled, but as a part of a linguistic and cultural minority. Others equate choosing a deaf child when it was possible to have a hearing child is at best selfish and misguided on the part of the parents, and at worst, child abuse. What do you think? What are the issues that underlie this debate?

7. How might PGD and similar practices impact the evolution of the human race?

8. What other events/situations in history mirror what is happening regarding PGD today? Can we learn from history?