

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

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.

Your family is a hard-working, average family. 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 ballet class, French lessons, and soccer camp. The company that sells the test claims children who are selected for “intelligence” may lead happier, more exciting and interesting lives. They could go on to better colleges, earn more money, and be better able to financially support their families.

You are planning to have another child, and are debating whether to have the child “naturally”, or to use this new PGD test to select an embryo with optimal intelligence. Each attempt to use this technique can cost approximately \$15,000. It takes typically between 2-12 months to get pregnant. Since this is a “non-medical” reason, none of it would be covered by insurance and your family would pay the full cost.

Do you trust this company’s claim? How do you come to a decision? What do you ultimately decide? Discuss the ethical and practical issues, from the perspective of:

- Parents
- Oldest child
- Yet-to-be-born second child

## **Scenario B: Congress considers regulating certain types of genetic testing**

You are all members of the US House Of Representatives. You are being lobbied by two groups on the subject of PGD.

The first group wants you to enact legislation that encourages and funds genetic testing and embryo screening – not just for diseases such as cancer or Alzheimer’s, but also for traits like intelligence, height, weight, and athletic ability. They argue that supporting this sort of work will lead to a happier, healthier, more productive society.

The second group is seeking a ban on all genetic testing of embryos for “social traits”. They believe that testing is pointless and inherently unjust, and will create even more division between the rich and the poor. They worry this will eventually lead to two distinct classes of people – a “genetic upper class” and the “biologically burdened”.

With which side will you vote? Who might these two lobby groups include- doctors, patient advocates, religious organizations? What might a “middle ground” solution look like?

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

PGD is commonly used to allow a couple to implant embryos that are free from a particular genetic disease. Often it is a fatal disease that will cause the child to die at a young age. Proponents argue that the child born after such a screening benefits because they are born without a fatal disease that runs in their 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 tissue donor for a gravely ill older sibling (Like Adam and Molly Nash). Often called a “savior sibling” this child will be a match to donate cells or tissues, or even an organ if needed.

In your family, you are planning to have another child, your second. 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. It is the only treatment option available. There is no guarantee a transplant will permanently cure your sick older child. This disease arose spontaneously; it does not run in the family and your second child would be very unlikely to have the same disease as your firstborn.

You are considering using PGD for HLA typing. This theoretical second child is not at risk for the disease your first-born has. PGD is being used only to select a child who is a match for your oldest. The hope is that this child will be needed to only donate stem cells. However, it is possible that this child may be called on to donate other tissues, such as bone marrow or an organ, sometime in the future.

Do you proceed to have the child via PGD/HLA? How do you explain to each child their different role or “purpose” in the family? What are the ethical and practical issues, from the perspective of:

- Parents
- Child who is ill
- “Savior sibling”

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

You're a member of the US House of Representatives. A bill has been brought forward to ban the procedure of PGD with HLA typing (i.e., the creation of "savior siblings"). 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 immunological match for a sick sibling.

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.

Referred to as "made to order" children, or even a "slave sibling", that 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. Children have a right to be born without this sort of agenda and burden, and need to be protected from their often well-intentioned parents, who when faced with the possible or likely death of another child, cannot be trusted to fairly evaluate what's best for a child born in this manner.

The other side, patient groups who want PGD with HLA typing to be allowed, argue that restricting a technology that can lead to healthier children, and can save the lives of children who are suffering, is unethical. As there are proven successes with PGD/HLA, it is a moral imperative to spare children and families of this suffering when at all possible. Because of the controversial nature of this procedure, there is no federal funding for research in this area, so people who take advantage of it are paying for it themselves, up to \$15,000 per attempt to get pregnant.

How do you vote? To allow it to continue, or to ban it? Are there other options besides these two approaches? What are they?