

# Selecting the Perfect Baby: The Ethics of “Embryo Design”

by  
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The research team assembled quietly in the lab. There were some difficult decisions to be made today. Kelly, a new research assistant, looked forward to the discussion. Privately, she hoped Dr. Wagner and the rest of the team would agree to help the couple that had appealed to them.

“Good morning, everyone,” Dr. Wagner began the meeting. “We have a lot to talk about. I’ll summarize this case for those of you who may not have had time to read the file. Larry and June Shannon have been married six years. They have a four-year-old daughter named Sally who has been diagnosed with Fanconi anemia. Sally was born without thumbs and with a hole in her heart. Shortly after her birth, she began suffering symptoms related to impaired kidney function and digestion that have only increased in severity. Fanconi anemia is a progressive disease that often results in physical abnormalities and a compromised immune system. Sally needs a lot of special care and has already had several surgeries. She can’t digest food normally or fight off infections as easily as a normal child would. If she doesn’t receive a bone marrow transplant, she will develop leukemia and die, most likely within the next three to four years. Neither Larry nor June had any clue they were both carriers of this disease.”

“A frightening diagnosis,” said Kevin, a research technician.

“Difficult to live with, as well. Not only will they probably lose this child, they must be crushed about the possibility of having another child with this illness,” commented Liz Schultz, the team’s postdoctoral researcher in gynecology and fertility.

“Exactly their problem,” continued Dr. Wagner. “The Shannons are interested in having another child and have approached us regarding pre-implantation genetic diagnosis (PGD). They are aware of the risks and the odds of success. They are anxious to begin the process as soon as possible.”

“Kelly, you’re new to the team, so let me summarize the PGD process for you. It’s a three-step process, with chances of failure and complications at each step. First, in-vitro fertilization (IVF) is performed. Some of June’s ova would be removed and fertilized with Larry’s sperm outside of June’s womb. If this procedure works, we should have several viable, fertilized embryos. Our second step is to perform genetic analysis on the embryos, removing a cell from each and testing for the presence of the Fanconi anemia genes. If we find embryos that are free of Fanconi’s, we can then perform the third step: implanting the healthy embryos back into June’s uterus.”

“Wait a minute,” said Kelly. “How many embryos are we talking about? They just want one child, not a half dozen.”

Dr. Wagner laughed. “Yes, I know. But during the in-vitro fertilization and implantation processes, we almost always have embryos that do not survive. There is only about a 23% chance of any implanted embryo thriving. There is a better chance for a positive outcome when we remove and fertilize multiple ova. In this particular case, the odds of a multiple pregnancy are very small, given the limitations on the ova we will be able to implant.”

“OK, I know I don’t understand all of this. But how can Mrs. Shannon produce that many eggs all at the same time?” asked Kelly. “She wouldn’t normally do that, would she?”

“No,” said Liz. “So before we even begin any of these procedures, June would have to take hormones to increase the number of ova she releases. As Dr. Wagner said, there are risks involved with every step of this procedure. Hormone therapy can have some side effects, including mood and cognitive effects. Some women suffer physical complications as well, although this is relatively rare. There are some studies that link hormone therapy to increased risks of ovarian cancer, although there is other research that contradicts that.”

“Plus,” Dr. Wagner added, “along with the risks to June, there is no guarantee that the procedure will be successful. Many couples must undergo the IVF procedure more than once before the implantation is successful in producing a healthy, full-term baby. In this case, it will be even more complicated because we cannot use all of the fertilized embryos but must limit ourselves only to those that are free of Fanconi anemia.”

“But we’ve done several of these types of procedures with a pretty high rate of success,” said Kevin. “Why should this one be different? You’ve screened the couple, right, and you said they’re aware of the risks?”

“Yes, but this case is very complicated.” Dr. Wagner sighed. “The Shannons have requested not only a Fanconi-free child, but one that will be a perfect bone marrow match for Sally. Sally’s illness may be treated with a transplant of healthy cells into Sally’s bone marrow. Because Fanconi’s patients are so fragile, however, the donor’s cells have to be a near perfect match, and that’s hard to find. Siblings are the best bet. In the meantime, Sally’s condition is deteriorating. The Shannons naturally want to give Sally as many years of normal life as possible so they want to take aggressive action. They want to cure Sally’s disease by planning and creating another child with specific genetic markers.”

“How would that work?” asked Kelly.

“You’ve heard of stem cell research?” began Liz. “Stem cells are special cells that can produce all the different organs and tissues of the human body. They are found in embryos or fetuses, and are usually obtained for research from embryos that die or are rejected in fertility procedures. That is the kind of research that has been so politically controversial lately. But a less potent type of stem cell is also found in adult humans and can also be obtained from umbilical cord blood. If we were to help the Shannons, and the procedure was successful, the blood from their new baby’s umbilical cord could be used for Sally’s bone marrow transplant, resulting in no injury at all to the baby and a possible cure for the worst symptoms of Sally’s illness.”

“The Shannons are suggesting that we perform the PGD procedure as we normally do, but select only those embryos that are both free of Fanconi anemia, *and* are also a perfect match for Sally,” said Dr. Wagner. “This presents some real ethical dilemmas for us. We have never tried this before. People have had PGD done to detect and prevent a variety of illnesses in their children, just as we have done here

before. But what we are proposing now would be selecting for a specific combination of genetic traits, a combination that will not benefit the planned child but will save an existing child. We will be selecting an embryo and then using it essentially as a blood donor for its sibling. It will be umbilical cord blood, which would be discarded anyway, but it's still a controversial procedure. If we agree, it also means we will be destroying embryos that are perfectly healthy, but are just not a match for Sally. I'm interested in pursuing this, but these are serious issues to consider. Not the least of which is that we may have trouble getting it approved. Before I run it past the review board, I want to know how you all feel about trying it."

"Well, I say go ahead with it. It will be a genetic breakthrough. In time, we'll be able to prevent all kinds of problems with this procedure. Why not start now?" urged Kevin. Another doctor on the team who had remained silent nodded her head in agreement.

"I'm not sure yet how I feel about this," said Liz. "I feel a little uncomfortable with the precedent this might set. We'll be opening the door to who knows what type of genetic selection. Do we want the responsibility for that?" A couple of others on the team seemed to side with her.

"Yes," said Kelly. "But think about the poor Shannons. And especially Sally. Does she deserve to suffer just because we're arguing about ethical problems of the future?"

"Well, it sounds like we all need to talk about this some more before we can reach a real consensus," Dr Wagner concluded. "I don't want to start on a case this important without everyone's agreement."

### **Review Questions:**

1. How could baby Sally inherit Fanconi anemia even though neither parent suffers from it?
2. What other illnesses or developmental disabilities can be inherited in this way?
3. What are the odds that the Shannon's second child would also have this disease?
4. What are the basic processes of IVF and PGD?
5. What risks are involved in this whole procedure?
6. How could a sibling's blood help cure Sally?
7. How could PGD be used to create that sibling?
8. What is so unusual about the PGD proposed by the Shannons?
9. What are some ethical issues related to the use of IVF? What are some ethical issues related to the use of PGD? What do you think about those issues?
10. What do you think the research team should do? What should the Shannons do?