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Why Infertility Patients Are Donating Embryos

Sixty percent of infertility patients are willing to donate extra embryos to research

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After a successful series of infertility treatments, Kristen Cohen and her husband, Lee, had two sets of twin boys, now ages 6 and 2. They also had about a dozen embryos that they no longer needed but could not imagine going to waste. "We went through so much to create these embryos," says Kristen. "This was much more than blood, sweat and tears." The Cohens had also benefited firsthand from medical research; Lee, who has cystic fibrosis, has been helped by advanced treatments. So in 2006, when Kristen saw an article about the Harvard Stem Cell Institute, she contacted it and began the process of donating their embryos, which could be used to create new lines of embryonic stem cells. After five months of paperwork and counseling for the couple, the Cohen embryos were in the hands of researchers. "We know they might be destroyed without making a single stem-cell line," Kristen says. "I don't need to know that my embryo helped save patient X. It's the greater good."

In the ongoing, often-heated debate over embryonic-stem-cell research—last month President George W. Bush once again vetoed a stem-cell bill, one that would have authorized federal funding for research on surplus frozen embryos—one party has been largely unheard from: the owners of the frozen embryos. "These embryos have very special and moral meaning for the people who create them," says Ruth Faden, head of the Johns Hopkins Berman Institute of Bioethics. "If we want to engage deeply with what ought to be done, we need to know their preferences." Now, thanks to the efforts of Faden and Anne Lyerly of Duke University, we do.

A recent survey the two conducted of more than 1,000 infertility patients found that 60 percent were willing to donate their frozen embryos for stem-cell research. Only 22 percent were interested in donating their embryos to another couple, while 24 percent indicated that they were likely to discard them. Faden calls the results "hugely surprising," especially when compared with the only previous national survey, from 2003, which found that slightly less than 3 percent of patients were interested in donating for science. That data, Faden notes, came from a survey of infertility clinics, not the patients themselves.

Couples who choose research often attribute the decision to the wonders and hardships of infertility treatment. "Once you've been through it, you're so appreciative of the science," says Amanda Bergen Peressutti. "So much has gone into helping you have this baby that I personally have a debt of gratitude. I want to do anything that I can do to help others." Bergen Peressutti and her husband, Gian-Carlo Peressutti, spent three years trying to conceive their first daughter. In clinic waiting rooms they saw dozens of others struggling with the same problems. After that experience, Gian-Carlo could not imagine discarding the embryos. "Terminating those embryos when they could potentially be of use to another person, in my mind, was like not checking the box on the back of your license to be an organ donor." The couple donated their additional embryos to a stem-cell lab in New York last month.

Other infertility patients choose not to offer their embryos for stem-cell research. Michelle DeCrane and her husband, Barry, whose daughter was born in February, have six embryos in storage. And that, says Michelle, is where they will stay while the couple decides whether to have more children (indecision is the reason many embryos remain stored). "For me, it would be destroying my children," she says. "That's a human life that we created."

The clear preference revealed in the survey for research over adoption appears to grow out of a sense of kinship. "They're a bunch of cells that could grow into your child," says Bergen Peressutti. "I'm just not comfortable having that child out in the world being raised by somebody I don't know and didn't choose." When infertility patients make their embryos available to other couples, they typically relinquish the right to know who gets them or even if they are used at all.

The willingness of infertility patients to donate their frozen embryos to science could have a tremendous impact on stem-cell research. While the ban on federal funding for research that destroys human embryos is a roadblock, the lack of embryos for private and state-funded research is also a major obstacle. "Right now, the flow of human embryos to stem-cell research is at a trickle," says Susan Fisher, acting director of the Human Embryonic Stem Cell Center at the University of California, San Francisco. "What we need is a flood." Faden estimates that if even half of those surveyed who say they are willing to donate actually did so, it could mean an additional 2,000 to 3,000 stem-cell lines. That is about 100 times the number of federally funded lines currently available. The survey by no means indicates that a steady supply of embryos will become available—many willing couples may never donate—but it does add a new and necessary voice to the discussion, one that, until now, has rarely been heard.