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Each stored embryo is a stem cell debate

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By **Andrea Stone, USA TODAY**

SAN DIEGO — Ingrid Jansson peers through a vapor of liquid nitrogen at frozen embryos conceived for her in a petri dish four years ago. It's the first time she's eyed the surplus from the in vitro fertilization procedure that brought her son Dylan, now 3, into the world.

"It's surreal," says Jansson, 39, as an embryologist fishes out the thin straw containing eight embryos stored at a fertility clinic where she was treated and now works as a nurse. "I don't think about them much, because I have two (children) at home that keep me busy."

As Congress renews debate about funding stem cell research using human embryos, people such as Jansson are thinking hard about what to do with excess embryos after their families are complete. Only they — not politicians, doctors or ethicists — are legally entitled to make the call.

It's not easy, even for Jansson, who does volunteer work helping fertility patients donate their leftover embryos to the Stem Cell Resource, an embryo bank here that provides them free to researchers. She and her husband, Jon Gardner, 41, never imagined they'd have spares after all they did to get pregnant. Now they disagree on what to do.

Jansson, who is not religious, wants to donate her embryos for research. She says giving them to an infertile couple is "not an option" because it "would be like giving away my own child, my own DNA." Gardner is Catholic, and he objects. He says stem cell research, which dismantles embryos, is "destroying human life" and opposes it for his "son's siblings." Says Jansson: "It's very difficult for us to decide."

Much attention has been focused on potential beneficiaries of stem cell research, such as actor and Parkinson's patient Michael J. Fox. Less notice has been given to those who literally give up a piece of themselves to make research possible.

How they decide will help determine the future of research into embryonic stem cells, the master cells from which scientists hope to develop treatments for diabetes, Alzheimer's and other diseases. Scientists hope to find cures using adult or amniotic fluid stem cells, but researchers like George Daley of Harvard say they are not a substitute for embryonic stem cells, which potentially can become any cell in the body.

Behind the public controversy is a private decision with moral, ethical and religious considerations. It is made even more complex by financial restrictions on stem cell research by the federal government — the nation's largest funder of medical research — and a crazy quilt of state laws and programs.

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"It's a painful decision, so (patients) just put it off," says Lucinda Veeck Gosden, director of embryology at the in vitro fertilization (IVF) clinic at Weill-Cornell Medical School in New York. The clinic's 9,000 embryos fill 20 tanks, and storage is "a major problem," she says.

Fertility doctors create embryos by removing eggs from a woman's fallopian tubes and fertilizing them with sperm in a petri dish. Because of the pain and expense — one IVF cycle can cost up to \$10,000 — and a failure rate of more than 60%, doctors routinely

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create more embryos than they implant in a woman's uterus. Those left over are frozen for possible use later.

Critics say embryo banks that cater to stem cell researchers will encourage fertility doctors to produce even more embryos. "It's appalling," says Richard Doerflinger, an ethicist with the U.S. Conference of Catholic Bishops, which says life begins at conception and which opposes IVF as "the next step toward commodifying human lives as research material."

Others ethicists, such as Yuval Levin, executive director of the President's Council on Bioethics in President Bush's first term, say embryo banks may actually help avert undue influence on parents, because the banks try to "stand as a barrier between the researcher and the IVF clinic."

It is unclear how many embryos are stored at the nation's 450 fertility clinics. A 2003 study by RAND Corp., a think tank, estimated there were 400,000. Most were being saved for future fertility treatments. Just 2.8% were designated for research.

Some fertility doctors report storing embryos for a decade or more and say as many as 10% are abandoned. "There are people who just leave them and move and forget about them," says Richard Scott of Reproductive Medicine Associates in Morristown, N.J.

Patients with frozen embryos have four options: Discard them, give them to other couples, pay hundreds of dollars a year to store them at minus-310 degrees Fahrenheit, or donate them to medical research.

Many try to avoid controversy

University of Pennsylvania bioethicist Arthur Caplan says many IVF clinics don't discuss embryo donation with patients because of moral concerns or confusion about what's legal. Fertility treatment, not usually covered by health insurance, "is a cash business," he says. Doctors "are very sensitive to image," noting that clinics want to avoid anything that hints at controversy.

At Weill-Cornell, "we've avoided it," says Gosden. She says 54% of her clinic's patients who have finished their families ask to have their embryos destroyed, 43% donate them to basic science unrelated to stem cells, and 3% offer them to other infertile couples.

Stem cell research using embryos is legal in New York and all but a few other states.

In California, voters in 2004 approved \$3 billion over 10 years for stem cell research. Lawsuits by opponents have bottled up the money, but the state-funded California Institute for Regenerative Medicine expects them to be resolved soon and is soliciting grant proposals. At least four other states, including Illinois and New Jersey, fund embryonic stem cell research.

Without the federal government's financial support, though, scientists say progress toward cures using embryonic stem cells has been slowed.

On Aug. 9, 2001, President Bush approved federal funding for research on 78 existing stem cell lines derived from destroyed embryos. He banned the use of taxpayer dollars for research on lines created after that date. The move was a compromise to advance medical knowledge while addressing moral qualms.

Research in other countries, including Australia and Israel, has leapt ahead, says Evan Snyder, director of stem cell research at the private Burnham Institute here. He says most federally sanctioned lines were "garbage" because scientists rushed to cultivate them "under the deadline." The result, he says, were inferior lines, because they usually take months or years to develop. Today, there remain just 22 lines in the USA. Because they were nourished with material from lab mice, they are not suitable for human use.

"The new lines are better," says Snyder, whose institute maintains labs on separate floors to avoid mixing the federally approved colonies and the newer, privately funded lines. "They grow better. They are more manageable. They don't die as quickly."

Which is why the Democratic-controlled Congress took up a bill in its first week to allow federal funding for new stem cell lines derived from fertility clinic embryos that would otherwise be discarded. The measure would require written consent from patients, who could not be paid. The House of Representatives approved it 253-174. The Senate is likely to pass the measure next month.

Bush vetoed an identical bill in July and says he'll do it again. It's unclear whether Congress could muster the two-thirds support required to override his veto.

In the meantime, "there is this climate in which people may be worried" about supplying embryos to scientists when there is a lack of federal support for the research, says Mary Devereaux, a bioethicist at the University of California-San Diego.

Decision was 'a no-brainer'

Mary and Brian Brooks always knew they would donate any extra embryos to stem cell research. "We felt strongly that would be a very good and ethical and proper use for them," she says. "It was a no-brainer."

So after having two children by IVF and expecting a third this spring that was conceived naturally, the St. Paul couple last September called the New Jersey clinic where their 13 excess embryos were stored to ask how they could donate them to scientists. "They told us because of the current political climate, there wasn't any place taking (donated) embryos for stem cell research," says Mary, 32, a former art teacher.

Brian, 33, a scientist with two doctorates, was skeptical. He got on the Internet and discovered the Stem Cell Resource, founded in 2003 as one of the nation's first privately funded, non-profit embryo banks. When Mary phoned, Jansson answered. She said the couple would have to sign a four-page consent form that made clear they would not be paid for the embryos or any "discovery based on the use of your cells."

After the couple signed, the bank arranged for the embryos to be shipped to San Diego in a deep-freeze canister. The bank paid the \$750 cost. The embryos are now among 1,000 others, all frozen at less than five days old, stored in a 47-liter liquid nitrogen tank beneath a counter in an 8-by-20-foot lab. The bank's location is kept secret for security reasons.

When the embryos arrived, they were given a registry number. All identifying information was removed and sent to a data storage company in Los Angeles. Researchers who want intact embryos or stem cells removed from them must submit detailed proposals for approval by the bank's scientific review committee. No money changes hands. So far, the nearby Burnham Institute has created 21 new or potential stem cell lines from banked embryos in order to study cystic fibrosis and diseases caused by chromosomal abnormalities.

A handful of other organizations also connect embryo donors and scientists. One of the nation's largest fertility clinics, Boston IVF, has provided excess embryos to researchers at Harvard University since 2001. And the University of California, San Francisco, runs its own tissue bank to provide embryos to researchers.

The Stem Cell Resource gets three or four inquiries a week from prospective donors who hear about it through word-of-mouth. It doesn't advertise.

David Smotrich, a fertility doctor who runs an IVF clinic here, founded the bank with nearly \$300,000 of his own money. The aim, he says, was to combat what he calls the "stagnation" of the Bush policy and help speed cures. A nephew has autism and an uncle suffers from Alzheimer's. Smotrich, 43, says his passion comes from his immigrant grandfather, who taught him the Jewish concept of *tikkun olam*. "It means to better the world," he says. "It may sound corny, but that's the reason I originally got started in this."

One of his patients, Alexandra Chisholm-Chait, calls herself "a person of faith" but says government should not be "instituting religious morality on research." After \$250,000 in fertility treatment, including 14 rounds of IVF and a daughter born through a surrogate mother, she is weighing what to do with four embryos.

Chisholm-Chait, 44, is leaning toward giving them to another infertile couple. About 150 babies have been born that way since 1998, Levin estimates. Chisholm-Chait's husband, Nicholas Abboud, wants to donate them for stem cell research so more people could benefit. One thing they agree on is that they must come to an agreement. "What good is it serving anybody in a state of frozen perpetuity?" she asks. "They're not going away, so you have to decide what to do with them."

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