

Parents can now conceive babies whose cells can cure a sick sibling. But what if the pregnancy goes wrong?

A Law's Fetal Flaw

BY NELL BOYCE

Just about a year ago, a woman we'll call Susan lay nervously in a maternity ward. For five days, she listened to mothers in labor and families joyfully greeting new babies. But her own child was dying in her womb. A complication from a prenatal test had made her waters break far too early, after only 16 weeks of pregnancy, and the fetus had no chance of surviving. Susan's doctors wanted to remove it quickly, before infection set in, and they warned that delay could endanger her life. But still, for five agonizing days, she waited.

Hundreds of miles away, at the University of Minnesota in Minneapolis, doctors, lawyers, and ethicists argued about what to do. Could they legally and ethically use the doomed fetus as a source of transplant tissue, as if it were an organ donor? After all, the baby Susan carried was special. He was created, in part, to save his older brother's life.

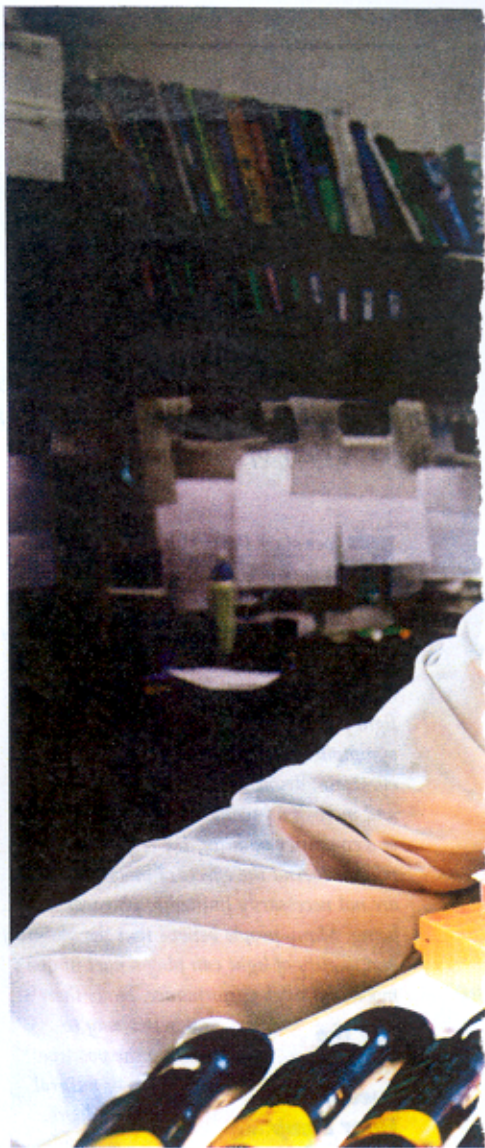
The story of Susan and her husband, whom we'll call Dan, dramatically illustrates how an emerging medical technology has run smack into a 10-year-old

law that restricts what can be done with fetal tissue. By genetically screening embryos, doctors can now help families affected by hereditary diseases conceive a healthy child. They can also screen the embryo's tissue type to make sure blood from the new child's umbilical cord can provide life-saving cells for a sick sibling. So far four ill children have successfully received transplants from specially conceived babies—including one just announced last Saturday.

But some families haven't been so lucky. Their pregnancies suffered complications that led to abortions—and that meant their fetuses were legally off limits as a source of tissue. The transplant

expert Susan and Dan consulted, John Wagner at the University of Minnesota, is a leader in umbilical cord blood transplants and knows the curative power of stem cells from matched siblings. He wants to be able to help parents in tough situations like Susan and Dan, but the law forbids it. "It didn't prepare for nuances in cases like this," says Wagner. Yet it's not clear how to change that law without potentially opening the way to a disturbing scenario: parents who start a pregnancy intending all along to abort it and harvest fetal tissue.

That idea never entered the minds of Susan and Dan; Dan calls it "a totally bizarre thought." Instead, they just want-



ed a family of healthy children. Their tale began several years ago, with the birth of their son "David." David needed surgery to fix a problem with his esophagus, one often associated with a genetic disorder called Fanconi anemia. His doctors tested him for the disease, and when the test came up positive, Susan remembers, she and Dan "cried like two babies."

Children with Fanconi anemia can seem fine at first, but over the years their bone marrow stops producing new blood cells. They often die in childhood if they can't get a transplant of blood-forming stem cells from a matched donor—and perfect matches are scarce. "We were scared to fall in love with him and lose him," Susan says. But as David grew into a toddler and his funny little personality shone through, Susan and Dan grew desperately attached and deeply afraid. "God, we don't want to lose him," says Susan. "We'd do anything."

And, in fact, they learned that they could do something. Three years ago, a couple named Lisa and Jack Nash tried a cutting-edge new technology to save

DOCTOR'S DILEMMA. John Wagner knew stem cells from a dying fetus might save a child but could not legally extract them.

their daughter Molly, who also had Fanconi anemia. The Nashes underwent in vitro fertilization to make multiple embryos in a lab dish, and doctors took a cell or two from each embryo for testing. They looked for the Fanconi anemia gene and also screened for embryos with the same tissue type as Molly's. Only healthy, perfectly matched embryos were used to start a pregnancy, and a son, Adam, arrived on Aug. 29, 2000. Wagner and his team took blood-forming stem cells from Adam's umbilical cord and used them to replace Molly's failing bone marrow. These days, Molly is a spunky 8-year-old who takes dance lessons, with a healthy little brother.

Susan and Dan decided to try the same thing. Fate seemed to smile on them—the doctors implanted one perfect embryo, and Susan got pregnant. "Everyone was practically celebrating," she says.

But after 15 weeks, sonograms sug-

gested something had gone wrong. An image of the fetus showed a large black space in the skull. "The doctor told me the brain was all water," recalls Dan. While the fetus didn't have Fanconi anemia, it seemed to have some other problem. Devastated, the parents called Wagner to ask an obvious question: If they decided to abort, could they still use the fetus's cord blood to save David?

Salvaging cells. Wagner knew the cord blood wouldn't contain enough stem cells at this stage of pregnancy. But the fetal liver is rich in blood-forming stem cells, and he thought tissue-matched fetal liver could provide the needed cells. Susan and Dan decided they would try to store the cells as insurance, in case David needed a transplant before they could conceive another matched child.

To make sure that whatever had gone wrong with the fetus hadn't hurt the blood-forming cells, the family went ahead with a previously scheduled amniocentesis test. The test took place on a Friday. Susan remembers sitting on the couch that afternoon at her mother's

house when suddenly her water broke. She and Dan rushed to the hospital and called Wagner again.

But Wagner had already turned to Jeffrey Kahn at the university's Center for Bioethics for advice. Kahn had uncovered a 1993 law that governs fetal tissue transplantation research. "It speaks very clearly to this situation," Kahn says. Any attempt to use these fetal cells, he realized, might be a felony that carried a fine and 10 years in prison.

The law was written at a time when doctors were trying to treat diseases

an who has an "induced" abortion can't direct the donation of fetal tissue to a specific person or a family member.

As Wagner points out, the case of Dan and Susan presents "the ultimate in directed donation. This fetus was tested, in part, to be a donor." And a medical procedure to remove the dying fetus could count as an induced abortion.

For days, Dan and Susan waited, trying to keep the fetus alive while Kahn and Wagner met with other experts and the University of Minnesota's lawyers to decide whether they could proceed. "It was back and forth over and over and over again," says Wagner. "We thought it was the right thing to do, and yet we couldn't figure out how to do it." Ultimately, the university decided it couldn't take the legal risk. Wagner understood, but he says: "I hated the decision."

It fell to him to call Susan and Dan. "That's when I think I finally got very upset," says Susan, who had remained calm during her five-day ordeal. "We were so angry that we couldn't do this." Dan remembers signing papers to have the fetus buried.

Ethicist Thomas Murray of the Hastings Center, who studies technology's effect on families, says the law created a cruel dilemma. "Let's have some sympathy. We can never read what's in someone's heart. But from what we can tell about their intentions, they were all in line with what it takes to be good, caring parents."

Trouble ahead. Similar cases are sure to come up, Wagner says. Lisa Nash nearly had a miscarriage during her pregnancy with Adam, whose cells cured his sister Molly. At the time, doctors thought about trying to collect the fetal

liver, but that pregnancy had a happy ending. Still, Wagner knows of another couple who, like Susan and Dan, went through embryo screening and then had to end the pregnancy, although they didn't ask about saving the fetal cells. And embryo screening is on the rise as more genetic diseases, including common conditions like sickle cell anemia, prove treatable with cord blood transplants. Wagner knows of some 30 families who have had IVF embryos screened for genetic diseases and tissue type.

"It's going to take a change in the law" to keep other parents from having to throw away tissue that might some day help a deathly ill child, says Wagner. "But how do you do that," he asks, without also creating a loophole that could lead to parents' making embryos to order and then aborting them to get tissue?

He knows of at least one couple, in a difficult situation, who seriously considered that route. Their son had adrenoleukodystrophy—the disease in the movie *Lorenzo's Oil*—a progressive nerve illness that is almost always fatal in boys. A transplant of cells from an umbilical cord can treat it, and the family decided to undergo embryo screening to try to have a healthy child who could be a donor. But as they started the process, the mother wondered what would happen if, instead of producing matched embryos totally free of the disease gene, they ended up with female embryos that had a milder version of the disease. Could they start a pregnancy and then abort it to get tissue that might ameliorate their son's illness?

Wagner said no, but the experience troubles him. He wonders what other transplant experts might do in the same situation. Not everyone would find the idea offensive. After all, abortion is legal in this country. And a few women have already had abortions as part of an effort to get tissue for a transplant. Before em-



HAPPY ENDING. The Nash family successfully treated Molly (right) with cells from baby Adam's umbilical cord.

ranging from diabetes to Parkinson's with cells transplanted from aborted fetuses. Early results looked promising, and government-funded researchers wanted to study the treatments as well. But lawmakers worried that women might get pregnant with the intention of aborting their fetuses to obtain transplant tissue for, say, a sick relative. Indeed, some women said on television that they wanted to do just that. So Congress passed a law holding that a wom-

CONCEIVING FOR A CURE

Embryo screening lets parents create a baby whose cells can cure genetic disease in a sibling.

1. Eggs meet sperm in dish, creating multiple embryos.

2. Doctors remove a cell or two from each eight-cell embryo for genetic testing.

3. Testing identifies embryos that lack the disease and match the sick child's tissue type.

4. Only those selected embryos are implanted in the mother's uterus.

5. After the baby is born, doctors collect blood from the umbilical cord.

6. Stem cells from the cord blood are transplanted into the bone marrow of the sick child.



bryo screening, some parents whose child needed a sibling-donor would get pregnant the old-fashioned way, gambling that the baby would be a healthy match. In at least three cases, older women worried about their declining fertility decided to have abortions when tests like amniocentesis showed that a healthy fetus was not a match; they wanted to try again as soon as possible. Embryo screening was meant to remove the incentive for such abortions—and Wagner abhors the ironic prospect that the technology could be used to generate fetuses destined to be destroyed.

Some legal experts think the current law on fetal tissue transplantation could be rewritten without opening the door to abuses. John Robertson at the University of Texas School of Law in Austin sat on a 1988 advisory panel on fetal tissue transplantation. "One could easily write an exception that would be workable," he says—a provision allowing directed donation if it would save someone's life and the abortion took place only because of danger to the mother or fetus. "Those exceptions weren't built into the law, and they clearly should be there."

Inviting abuse? Others disagree, among them Douglas Johnson, legislative director for the National Right to Life Committee, whose group opposes all abortions except in rare cases where the mother's life is threatened. His group fought the original law because it does allow research on aborted tissue, and he says changing it now to add any exceptions "would be to invite abuse."

Some find embryo selection itself morally repugnant, likening it to Nazi eugenics. "These procedures treat human beings at the earliest stage of biological development as a means to an end," says Joseph Howard, a Roman Catholic priest and biologist who serves on the bioethics committee of the American Life League. Add abortion to the mix, and the picture becomes "particularly gruesome," he says, "because it involves killing one life to save another."

Such passions explain why Susan and Dan wish to remain anonymous, even though they hope their story spurs a change in policy. "We can't let this happen to another family," says Susan, whose greatest fear is what will happen to David if they can't find a match. Since that awful week last year, she has tried twice more to get pregnant after embryo screening. The first time, the implanted embryos didn't start a pregnancy. The next time, this spring, she miscarried in the first trimester. "We lost our chance," she says, "because of this law." ●



CATCHING RAYS. SPF numbers don't rate sunscreens' ability to block harmful UVA light.

BY HELEN FIELDS



Beachgoers using sunscreen to prevent skin cancer might be rubbing themselves the wrong way—even if they are rubbing in lotion with a high SPF number like 30. SPF, or "sun protection factor," doesn't rate a type of sunlight that may play a crucial role in triggering cancer.

The danger light isn't sunburn red. It's a type of ultraviolet light called UVA, which seems to suppress your immune system and allow cancer cells to flourish. SPF numbers rate only protection from sunburn, caused mostly by another light type, UVB. But a hundred times as much UVA as UVB reaches Earth's surface. "Because there's so much more UVA, we find that the UVA wave band in sunlight is more important" to immune-system damage, says biologist Gary Halliday of the University of Sydney in Australia—a country of sun worshippers with the highest rates of skin cancer on the planet. There are compounds that block a lot of UVA, but you have to squint at the label to learn if your sunscreen has them. Don't rely on the large-lettered claims on the front of the bottle.

Scientists have recognized UVA's cancer-causing potential only in the past decade. Research has shown that mice can get skin cancer from UVA alone. In a study published this month in the *Journal of Investigative Dermatology*, Halliday and his colleagues smeared different

sunscreens on people's backs and shined ultraviolet light on them. Among the group, skin slathered in sunscreens that blocked more UVA had immune cells—the anticancer guards—that remained the most active.

The fine print. While sunscreens may claim they block UVA, their protection from that light isn't as strong as their UVB protection, says Vincent DeLeo, chairman of dermatology at St. Luke's-Roosevelt Hospital Center and Beth Israel Medical Center in New York. Bottles that say "broad spectrum" or "UVA" on the front do block some UVA. How well they protect you depends on the whole formula, says biologist Patricia Agin of Coppertone, the sunscreen company. (Indeed, Halliday found the same UVA blockers doing both well and poorly in different sunscreen formulas.) Agin says your best bet is to make a choice based on ingredients. Zinc oxide blocks the widest range of rays from the UVA spectrum, and avobenzone, also called Parsol 1789, is also effective.

The Food and Drug Administration hasn't decided yet how to tell companies to test for UVA protection, though the agency plans to release new rules for testing and labeling in 2005. This summer, read labels carefully. Protective clothing and a wide-brimmed hat will be a big help, DeLeo says. Lots of sunscreen that's higher than SPF 15 can aid you a bit: UVA causes some burning, so high-SPF sunscreens do block some UVA rays. Don't forget, DeLeo says, to re-apply it often. ●

