

Banking on a Cure

After Sandy Payne of Seattle, 36, labored for 10 hours to give birth to her first child, something unusual happened. First her husband cut the umbilical cord;

then her OB/gyn, Dr. Robert Levine, collected the leftover cord blood. That was seven years ago and Payne was a pioneer in the world of umbilical cord-blood banking. "My father and brother had cancer so I was determined to bank my children's cord blood," she says.

By the time she had her second child—whose cord-blood she also preserved—in 2003, banking cord blood had become better known. But many parents-to-be still don't know much about this relatively new practice and only first hear about it when they are busy making other decisions—during their first prenatal visit or in the hospital on labor day.

To break it down, it's all about stem cells, the body's ingenious mechanism for developing tissue and organ cells. Specialized stem cells have specific functions; for instance, blood stem cells grow into blood components. Research shows, however, that stem cells can also grow into other types of cells. When healthy stem cells are transplanted into patients with certain life-threatening diseases, such as leukemia and sickle cell anemia, the cells can potentially replace bad cells with healthy ones and eradicate the disease.

These miraculous cells come from multiple sources, including bone marrow, embryos, and umbilical cord blood. Although embryonic stem cell research has shown tremendous potential for curing conditions like Parkinson's, Alzheimer's, and spinal cord injury, it's controversial and limited by a ban on future federal funding. Bone marrow also has its drawbacks as a source. "In the past, bone marrow provided the best hope if a donor could be found that very

closely matched the patient's blood," says Dr. Joanne Kurtzberg, director of the Carolinas Cord Blood Bank at Duke University and the American Academy of Pediatrics spokesperson on umbilical cord-blood therapy. But "it's far easier to collect cord blood than bone marrow. Cord-blood stem cells are less mature and easier to match. They're less likely to

Should you save your child's umbilical cord blood? Here are the facts and expert insight you need to decide.

BY • JEANNE FAULKNER

be rejected by the patient's body."

Umbilical cord blood, proponents say, is the best option because it's easier to collect, poses no medical risk, and doesn't affect the delivery experience, except for the pesky paperwork. Congress seems to agree. A year ago, it passed the Stem Cell Therapeutic and Research Act (HR 2520), which was quickly signed into law, authorizing \$79 million in new federal funding to collect and store 150,000 cord-blood units in order to establish a national public cord-blood-bank network. With more than 4 million babies born in the United States every year, that's a lot of opportunities to save lives. So why isn't cord-blood banking standard practice—why isn't everybody doing it?

CORD BLOOD 101

Once a baby is delivered, the OB/gyn or midwife collects the blood left in the cord and placenta into sterile bags. The bags are shipped to a blood bank, tested for contaminants like HIV and hepatitis, separated into components (plasma, red blood cells), and cryogenically frozen in liquid nitrogen at 180 degrees below zero. When the blood is needed for a family member or stranger, it's taken out of deep freeze and transported to a hospital for transfusion. Then, hopefully, the stem cells work their magic in patients with conditions such as leukemia, sickle cell anemia, and aplastic anemias.

Banking the cord blood seems like a no-brainer, right? On the positive side, umbilical cord blood cells are more easily accepted by a patient's body than bone marrow and less likely to attack normal tissue. A sibling's collected cord blood has a 25 percent chance of being a perfect match. But there are cons to consider. Not all collected blood is usable. If the volume of blood collected is too low or a contaminant is identified, the sample is no good.

Furthermore, as a parent, you must choose between a public or private cord-blood bank. Public donation makes your child's cells available to anyone who might need them and increases the supply of ethnically and genetically diverse transplant units for patients worldwide. But you would not have guaranteed access to the cells for your own family. Private banks, which charge fees, do keep the cord-blood within your control, however it's unclear how long stored cells will last or if they'll provide any therapeutic benefit in the future. "The chance that most families will use their own banked blood is remote," says Dr. Jeffrey Ecker, a high-risk obstetrician at



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confusing decision," says Dr. Brian Drake, an obstetrician in Portland, Ore. "Parents get information on cord blood at their first prenatal appointment. No doubt, they'll also read about private banks who claim to provide insurance for their baby's future. Parents feel conflicted: obligated to provide the best for their child, but guilty if it's unaffordable. I invite them to discuss it with me and to do their homework."

If you choose to bank your baby's cord blood, make sure you understand the procedure and do research. "Labor was easy compared to all the homework on umbilical cord blood banking," says Sandy Payne. As you collect information, be sure consider these key questions:

- Does your hospital participate in donation to the national registry?
- Is the cord-blood bank on the National Marrow Donor Program's list of banks, ensuring it is FDA-approved?
- Is the bank accredited by the American Association of Blood Banks for the specialized processing of stem cells? Does it adhere to FDA standards, issued in 2005, for tissue and blood donation?

Massachusetts General Hospital and chair of the American College of Obstetricians and Gynecologists Committee on Ethics.

In fact, the percentage of privately banked successful blood transplants is small: 30–35 out of 400,000 cases, says Dr. Kurtzberg. This is a small chance of return on your investment, considering that initial collection and processing fees at private banks average \$1,000–\$1,500, with annual fees of about \$100. But to some, it's worth it. "The potential for use is very small right now, but could be very great in the future," says Robert

Gravely, vice president of marketing for Cryobanks International, a private bank that also provides public use. "Science is changing rapidly and you just don't know what could happen with it or to your family. Yes, it's expensive for a lot of families but we're all invested in the possibilities stem cells offer for the future."

MAKING AN EDUCATED CHOICE

With all of these complex factors, it can be hard to choose. "It's an emotional and

What Would Doctors Do?

WE ASKED PHYSICIANS FOR THEIR TAKE ON CORD-BLOOD BANKING.

"I'd donate to a public bank but wouldn't bank privately. With no serious family history, my money would be better spent on a college account."

Dr. Jeffrey Ecker, OB/GYN

"If donating to a public bank is easy to do, I'd consider it, but I'd recommend parents think long and hard about whether the private banking expenses are worth it."

Dr. Nancy Grant, OB/GYN

"If I knew then what I know now, I'd bank my children's cord

blood privately. My son has a bleeding disorder, and I know his banked blood wouldn't help him now. But who knows? In the future, with genetic engineering, it might be really important."

Dr. Oscar Polo, OB/GYN

"I would definitely bank my child's blood in a private bank. Stem cells are going to be even more important in the future as a tool for all kinds of diseases, like heart disease. If a close family member needs the blood, it's available. If it's unaf-

fordable for parents, I'd recommend donation to the national registry for research and transplant, but I think competition in the market will make it less expensive eventually."

Dr. Roseline Dauphin-Baptiste, OB/GYN

"I almost never recommend private banking. I tell patients it's the most expensive insurance policy you'll probably never use. But, in the case of a patient with, say, multiple sclerosis, it couldn't hurt. You never know

what kind of stem cell therapy will develop. Since embryonic stem cell research is being restricted, cord-blood research might offer some hope for some of these illnesses."

Dr. Maxine Bauer, OB/GYN

"I wouldn't waste my money on private collection. There's enough to pay for when raising children. If my child needed a cord-blood transplant, I know the blood will likely be available through the public banks."

Dr. Brian Drake, OB/GYN



- ▶ How many units does the bank process? Bigger numbers may mean more experience, transplants, and quality assurance.
- ▶ Can you switch your sample to another facility later? The industry is changing quickly. Competition may lead to better facilities down the road.
- ▶ Where is the bank located and what security measures are employed?
- ▶ Are the laboratory and storage facility owned by the bank? You want all connected facilities to have the same standards.

As with any other decision involving your child and family's future health, get advice. Talk it over with your doctor, extended family, and any friends who have banked blood. (See "What Would Doctors Do?" p. 100.)

FUTURE OF BANKING

Because the American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists both discourage private banking (emphasizing the extremely rare chance of use), some private banks have changed their game plans. Dr. Bertram Lubin, president of Children's Hospital Oakland and an AAP spokesperson on cord-blood banking says, "Some private banks, like Cryobanks International and ViaCell, are evolving and working with medical providers and scientific researchers in new ways. Some realize they have to be more thoughtful in the statements they make to families. It's true there might be a lot of change in this industry's future but they need to be

cautious about overstating their claims, especially in light of the data."

Although collection and storage at a public bank is free, if you're not delivering near one, donation might be difficult. Cryobanks International started providing private storage in 1995 and soon became the first and only private bank to accept donation of units for the national registry free of charge from anywhere in the United States (if there's no public bank in proximity). It currently has 8,500 units registered with the Bone Marrow Donors Worldwide and Caitlin Raymond International Registries, in addition to its roster of privately stored units. Many other private banks now provide sibling-donor programs with free collection and processing services for families in need.

Children's Hospital Oakland Research Institute (CHORI) had the first and only program ever funded by the National Institutes of Health, which aimed to establish the highest standards, ensuring successful transplant of sibling-donated cord blood. As funds dwindled, CHORI sought a private partner, the ViaCord subsidiary of ViaCell, to keep the programs viable. Since May 2006, CHORI/ViaCord has offered free or low-cost collection, banking, and transplant services to families with a child currently suffering from a disease treatable with stem cells. "We're basically running the same program as before but now ViaCell banks our units at their cost. They're able to go out to OBs across the country and tell them what we're doing," Lubin explains. Of the 2,000 units CHORI has collected since its inception, 500 matched and 70 have

As with any decision, talk it over with your doctor, family, and friends.

been released nationwide, with an 85 percent successful transplant rate.

With so many plans and decisions to make, no parent wants to entertain the possibility that their baby might one day face a life-threatening disease. Whether or not you choose to bank cord blood, you can rest assured that the potential cures are out there and multiplying. ▶

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Resources

National Marrow Donor Program
www.marrows.org, 800-MARROW2

National Cord Blood Program
www.nationalcordbloodprogram.org
866-767NCBP

Children's Hospital Oakland Research Institute
www.chori.org, 510-450-7605

Cryobanks International
www.cryo-intl.com, 800-869-8608

ViaCord
www.viacord.com, 866-668-4895

NeoCells
www.neocells.com, 888-50-CELLS

Cord Partners
www.cordpartners.com, 888-882-CORD

CorCell
www.corcell.com, 888-326-7235

Cord Blood Registry
www.cordblood.com, 888-932-6568

Cryo-Cell
www.cryo-cell.com, 800-STOR-CELL

Family Cord Blood Services
www.familycordbloodservices.com,
800-490-CORD

A Parent's Guide to Cord Blood Banks
www.parentsguidecordblood.com