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How to decide if you should save your newborn's umbilical fluid

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BODY:

To save or not to save? That is the latest question expectant parents are being pounded with these days, as they decide whether to bank their newborn's umbilical cord blood for possible medical use later in life.

"It's like insurance," says Dr. Lawrence Horn, a gynecologist in Huntington. "I've been recommending it for a few years." Not just for the baby but for the potential health benefit of siblings, parents, even complete strangers.

Cord blood is rich in stem cells, which are the building blocks of the immune system and all other blood cells. Saving it, says Horn, virtually guarantees you'll have genetically matched stem cells on hand in the tiny chance that the child or someone else in the family suffers from a treatable blood disorder or needs a bone marrow transplant. Even people unrelated to the donor could be a genetic match.

So far, cord blood stem cells (not to be confused with controversial embryonic stem cells) have been used in about 6,000 transplants to treat leukemia, lymphoma, blood disorders and some genetic diseases. Scientists say they believe cord blood might soon be used to repair heart or nerve tissue damaged by strokes, Alzheimer's and Parkinson's diseases or spinal cord injuries.

In the meantime, Congress is considering legislation that would create a federally funded national registry of donated cord blood, which has successfully been used in stem cell

transplants between unrelated people.

Still, saving cord blood in one of the nation's dozen or so private banks costs about \$2,000 initially, then \$100 a year to maintain storage. Even with long-term low monthly payment plans, banking cord blood is expensive.

And just as with all the other hotbed issues of **pregnancy** and childrearing - breast-feeding, bedtimes, day care - there are a dizzying number of facts to consider on both sides of the issue.

"This technology is going to be the future of medicine," says Dr. Richard Roberts, attending physician at Long Island Jewish Medical Center in New Hyde Park. He strongly supports banking cord blood, as long as people understand "you're spending money on something we don't have an answer for."

Indeed, major medical associations haven't been wooed. The American Academy of Pediatrics is currently not encouraging parents to bank cord blood privately as "biological insurance," but not discouraging it if someone in the family might need a stem cell transplant.

"It's all basically a gamble as to whether or not you're going to use it," says Sunnyside resident Jeremy Kareken, who has a 2-month-old son. Guilt and paranoia about doing "the right thing" for their child may drive some parents to bank cord blood, but for Kareken and his wife, Gail Griffin, it was all about the future of stem cell research. "I'm very pro-science," says Kareken, a 35-year-old television producer.

Commack residents Adam and Tracy Bernson saved their 2-year-old son Aaron's cord blood despite not hearing any encouragement from their doctor. They'll do it again today when their second son is scheduled to be delivered by Caesarean section. "You take precautions with everything else in life," says Tracy, 32. "If there's a 1 percent chance it could save my family in the future," it's worth the money.

All the medical experts interviewed for this story agree parents facing the decision on whether to bank should consider three major factors: ethnicity, family history of disease, and finances.

Minorities in need of bone marrow transplants have a harder time finding genetic matches through adult donor programs or public umbilical cord blood banks because most of the holdings are from white donors, says Roberts. They and interracial couples should try to bank privately or make arrangements to donate for the potential benefit of a third party.

Anyone who's had a relative go through a stem cell transplant or has a family history of immune system diseases or cancers probably wants the peace of mind of having genetic cord blood on hand, says Charles Sims, a pathologist and co-founder of the private bank, California Cryobank.

And for everyone else, it's all about the money. "It would be a very clear-cut decision if there wasn't financial stuff involved," Roberts says.

Ultimately, he says, it's up to the parents to decide.

Ollie and Marisol White, of Port Jefferson Station, have spent hours over the past few months researching what's known and not known about cord blood. When their twins are born next month, they won't be saving the cord blood.

"We understand it could be life-saving," says Ollie, a police officer. But given how new the science is, how rarely a child's own cord blood has been used to his or her benefit and the significant cost to store privately, it's not the right choice for their family.

How it works

Cord blood is collected right after the baby is delivered. The process, doctors say, doesn't harm the child or the mother.

After the umbilical cord is clamped, the physician draws about 4 ounces of fluid from the cord or placenta and deposits it into a sterile kit that's rushed by courier to the banking facility the parents have chosen. There, the unit is processed and deeply frozen for indefinite storage. Arrangements need to be made in advance so the collection kit can be sent to the parents and brought to the hospital the day of the baby's delivery.

Those who decide not to store their child's cord blood privately might be able to donate it to one of the country's 22 nonprofit public banks.

The oldest and largest is New York Blood Center's National Cord Blood Program. The trouble is, the center can afford to collect cord blood at only one Long Island hospital - North Shore University Hospital in Manhasset. And that's only if the mother is eligible and the baby is delivered Sunday through Friday morning, according to the program's Web site.

While the program will be expanding to Long Island Jewish Medical Center in New Hyde Park, it also collects, with similar restrictions, at New York- Presbyterian Hospital Weill Cornell Medical Center in Manhattan and the Brooklyn Hospital Center.

More than 100,000 newborns have their blood on file at Arizona-based Cord Blood Registry, the country's largest private bank, says co-founder Steve Grant. About 30,000 of those have arrived in the past year, marking a surge in business since the bank opened in 1995.

Dr. David Harris, CBR's scientific director and a professor of immunology at the University of Arizona, estimates that a quarter of a million babies have had their cord blood banked privately nationwide since the early '90s. An additional 60,000 to 70,000

units have been donated to public banks, which function under the same concept as organ donor registries. The House of Representatives recently approved a bill granting \$79 million to build a national public registry of at least 150,000 donated cord blood units. The future of that legislation rests with the Senate.

In the early years, Sims says, people thought they were banking their newborn's cord blood exclusively for his or her benefit. "Nobody does that anymore," says Sims. It became apparent that many diseases - certain kinds of anemia, leukemias and non-Hodgkin's lymphoma, to name a few - can't be treated with a child's own cord blood because the cells in the stored unit could carry the disease, too.

Private and public

That was the case for Vic and Tracey Dones' son, Anthony, now 3. The Levittown residents paid a few hundred dollars in 2002 to bank their son's umbilical cord blood as "a security blanket" in case anything should happen. Then he was diagnosed with osteopetrosis, a rare bone disease and needed a stem cell transplant. Tracey Dones says she was shocked when doctors told her that Anthony's stored stem cells couldn't be used.

Fortunately, a compatible cord blood unit was plucked from NYBC's donations and the stem cell transplant was successful. Tracey Dones is still feeling deceived by the private company she banked with, saying advertisements "absolutely misled" her into thinking Anthony's own cord blood would save him if he got sick.

She urges expectant parents to donate cord blood to public banks or to at least realize they'll probably never use it.

"If you assume that the only use is for that child or that you can only store it for 10 years, then that argument is true," says Sims. "We argue these cells will be good for decades and the potential beneficiaries are the entire family."

At CBR, about 40 stored cord blood units have been thawed and used in treatments, Grant says. Mostly, it's been to treat a donor's sibling who has childhood leukemia. "There's going to be minimal use right now because there aren't too many kids who have their blood banked," Grant says.

WHAT YOU SHOULD KNOW

Parents who ultimately decide to bank their child's cord blood should carefully consider which company they'll be doing business with. And there are several legal considerations as well. Retired attorney Brette **Sember** recommends several tips in her book, "Your Practical **Pregnancy** Planner" (McGraw Hill, \$14.95):

Check that the bank is registered with the Food and Drug Administration and accredited by the American Association of Blood Banks.

Make sure some cord blood that has been preserved at the facility has actually been thawed and used. Ask about the success rate.

Fees for transportation and processing should be clearly stated in the contract.

Find out what happens to your baby's cord blood should the facility close, lose power or be sold. Is the banking facility insured for natural disasters?

What if your baby's cord blood is not drawn, lost in transit or otherwise damaged? You should be entitled to a refund.

Your contract should detail the process for requesting withdrawal of a sample. Be sure you understand what documentation you'll need. - SHAWNA VANNESS

WHERE TO GO

Private cord blood banks:

Cord Blood Registry, www.cordblood.com, 888-267-3256

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

Cryo-Cell International,

www.cryocell.com,

800-STOR-CELL

Family Cord Blood Services, www.familycordbloodservices.com, 800-400-3430

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

Public cord blood banks:

New York Blood Center's National Cord Blood Program collects donated cord blood at three New York metropolitan-area hospitals: North Shore University Hospital, Manhasset; the Brooklyn Hospital Center, 121 DeKalb Ave., Brooklyn; and New York-Presbyterian Hospital Weill Cornell Medical Center, Manhattan. For more information, go to www.nationalcordblood

program.org.

Compiled by Shawna VanNess