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'Biological life insurance' catching on

More and more parents banking cord blood of newborns

By KELLY BOTHUM, The News Journal

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Expectant parents already have plenty of decisions to make before baby's big day arrives. Epidural or natural childbirth? Cloth or disposable diapers? Bottle or breast?

There's another choice parents have -- what to do with the blood in their newborn's umbilical cord. In most cases, it's thrown away as medical waste. But inside that cord are hundreds of millions of blood-forming stem cells that can be used to treat patients with blood diseases such as leukemia. Rather than discarding this source of stem cells, more parents are opting to put it to what they say is good use.

They're paying up to \$2,000 to have their newborn's blood drawn from the umbilical cord moments after birth. Those stem cells -- usually about 3 ounces' worth -- are taken after the umbilical cord is clamped, then quickly frozen and stored. Parents pay an annual fee -- usually \$100 to \$200 -- to keep the stem cells stored, all the while hoping there won't be a need for them.

It's a quick procedure, painless to the mother and child, but advocates say it gives parents some needed peace of mind, especially if there is a history of blood diseases in the family. Cord blood has been used to treat leukemia, sickle cell anemia, aplastic anemia, Hodgkin's disease, non-Hodgkin's lymphoma and about 70 other blood-based conditions.

"It's an insurance policy to me for my children," said Sissy Harris, of Greenville, who banked the cord blood of all three of her children. "The best thing in the world is if we never use it."

Nearly eight years ago when Harris told people what she planned to do, she got lots of raised eyebrows in response. Her obstetrician supported her choice, but few people even understood what Harris was doing. After her eldest daughter, Katie, was born, hospital staff followed a step-by-step list of instructions to make sure the collection was correctly procured.

By the time her youngest daughter, Margot, was born 19 months ago, cord blood banking had become more commonplace. Even the complimentary bags handed out at her doctor's office advertised cord blood banking.

Although her family has no history of blood diseases, Harris said the decision was a no-brainer to her.

"I guess because I'm able to bank, I like knowing it's there for each of them," she said. "It's a gift to give them."

Argument against private banking

Few people would dispute that cord blood is valuable, but not everyone agrees with the idea of privately banking this source of stem cells. Earlier this month, the American Academy of Pediatrics issued a recommendation for families to donate cord blood rather than bank it privately. In issuing its statement, the organization estimated the chances of a child needing its own cord blood at one in 1,000 to one in 200,000. Only parents who have an older child with a condition who might benefit from a stem cell transplant are encouraged by the academy to privately store their newborn's cord blood.

Children with a genetic disease such as sickle cell anemia can't be treated with their own cord blood because the blood

cells already have the disorder. Many physicians also say there isn't enough data to say children can be successfully treated with their own stem cells.

But Steven Grant, vice president of communications for Cord Blood Registry, the largest of the nearly two dozen private cord blood banks nationwide, calls that notion out of date. His firm has banked the cord blood of about 160,000 babies since it was created 12 years ago. In that time, there have been 45 cases of those stem cells actually being used. In some cases, the cord blood was used by the mother or a sibling, but the last six were used by the children themselves in a procedure called an autologous stem cell transplant, Grant said.

He said the private banking of stem cells ensures children can have access to the best treatment option if they need to be treated for a blood disease. Using a cancer patient's own banked stem cells doubles their rate of survival, reduces their risk of rejection and minimizes other complications, he said.

Most clients with cord blood banked are still children -- one-third are under age 1 -- and at an age when they are least likely to have cancer. But as they get older and scientists develop other uses for cord blood, they may be glad their families made the decision to save it.

Grant dismisses accusations that private banks are taking advantage of parents at a time when they are most vulnerable by guiltting them into banking cord blood as a way to protect their children in the event they develop a blood-related disease.

"In our situation, we are trying to convey the potential value of our service at an inopportune time," said Grant, one of the co-founders of the company, which stores cord blood in an 80,000-square-foot building in Arizona. "But it is not dictated by us. It's dictated by nature. This is something you have to know about before the baby is born."

Two beneficial options

Dr. Stefanie Marshall, an obstetrician/gynecologist with First State Women's Care, doesn't keep tabs on the number of women pursuing cord blood banking, but estimates that less than 5 percent of her patients pursue the topic and only about 1 percent wind up privately banking their newborn's cord blood.

"It's usually, 'Should I do this?' and then, of course, 'What's the difference?' " said Marshall, who is affiliated with Christiana Care Health System. "The way I tell patients, I view it as biological life insurance. You don't really know. You pray to God you don't really need it."

Grant likens private cord banking to opting for private school for some parents.

"The two systems [public donors and private banking] exist harmoniously based on individual preference," he said. "The more people choose to bank for their family, the less the need to call on public supply. We in no way limit public access. We need a public system for cord blood donations and we're trying to create awareness for a public system."

Carolyn Kohn, of Wilmington, banked the cord blood of all three of her children. One of them, Brady, needed it after he was diagnosed with aplastic anemia at age 2. The transplant worked, but Brady died in 2002 from an infection.

Since then, Kohn has tried to raise awareness about the benefits of cord blood and make sure the precious commodity doesn't go to waste. She and her husband, Andrew, started the Brady Kohn Foundation to educate families about cord blood and raise money for research.

Kohn, who gave birth to a girl, Charlotte, in May, said she doesn't care which decision a family makes -- to donate cord blood or bank it for themselves -- as long as they don't discard it.

"Whatever they choose, we will support them," she said.