

## **``I HOPE I THREW THAT MONEY AWAY" SAVING CORD BLOOD EASES PARENTS' FEARS< GROWING SERVICE PROVIDES PEACE OF MIND, BUT SOME ETHICISTS WONDER IF IT'S WORTH IT**

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Lisa and Tim Edwards made all the typical preparations for their first child - choosing a name, buying clothes, furnishing a room. But they also took another, rather unusual step.

They talked to their obstetrician about saving the blood from their baby's umbilical cord after delivery and arranged for a cord blood bank to store it.

If their baby, Ian, now 9 months old, ever develops leukemia or a handful of other blood disorders, the cord blood might save his life.

There is no guarantee, however. Cord blood transplantation, used as a substitute for bone marrow transplantation, is still considered an experimental treatment.

And chances are slim that Ian or anyone else in the Edwards family will ever need the cord blood.

But an increasing number of families, like the Edwardses, are choosing to save their children's cord blood just in case. The cost is about \$1,300 to collect and process the blood and \$100 a year to maintain it.

To meet the growing interest, Bon Secours Health System this week will begin giving information about cord blood banking to women in its prenatal classes and to obstetricians who deliver at DePaul, Maryview and Mary Immaculate hospitals.

Some doctors and parents welcome the move. Cord blood is a valuable resource that can only be collected at birth, they say, and parents should be able to decide whether to store it for their own use, donate it or throw it away.

But others worry that cord blood companies profit from the unproven technology by capitalizing on parents' instincts to protect their children. And depending on how information is presented, they say, storing cord blood could seem more a necessity than an option.

``Parents are vulnerable from the standpoint that they want the best for their children," said Lisa Eckenwiler, bioethics expert and assistant professor of philosophy at Old Dominion University. ``The question is how to help people make truly free and informed decisions."

Lisa Edwards of Norfolk heard about cord blood banking early in her pregnancy.

Her sister, a doctor in Phoenix, was also pregnant and planning to bank her child's cord blood. She told Edwards about it, and Edwards told her husband.

``We both felt like it was buying insurance," Lisa Edwards said. ``How quickly can each of us spend \$1,300? If it means my child's life, it's a small price to pay."

The Edwardses knew cord blood treatments were experimental. They knew there was a slim chance - estimates varied from 1 in 1,000 to 1 in 200,000 - that they'd ever need it.

But Lisa Edwards had an aunt with leukemia, and Tim Edwards had a cousin who died of childhood leukemia. They'd heard stories of children whose lives had been saved by cord blood transplants. They didn't think twice.

They contacted Cord Blood Registry, a California-based company, and paid \$295 to enroll in the program. The company sent them a collection kit to bring to the hospital.

And on June 11, 1999, when Ian was born, their obstetrician collected the cord blood. They mailed the blood to Cord Blood Registry the same day and paid another \$995 to have it processed and stored for a year.

"I paid the money and I hope that I never have to use it," Lisa Edwards said. "I hope I threw that money away, and I'm sure that's how most parents feel."

Like bone marrow, blood from the umbilical cord and placenta is rich in stem cells, the building blocks of all blood cells.

Stem cells can be transplanted to restore bone marrow that has been ravaged by certain inherited blood disorders or by high doses of chemotherapy or radiation used to treat illnesses such as leukemia.

For years, doctors have used the stem cells from bone marrow for such transplants.

But bone marrow requires a perfect match between donor and recipient. Finding that match - especially for minorities and people of mixed racial heritage - can be a grueling and lengthy process.

Stem cells from cord blood tolerate slight mismatches, reducing the risk that the body's immune system will attack the new cells - a potentially fatal complication.

Harvesting bone marrow also requires the donor to be anesthetized before a needle is inserted deep in the hip. Collecting cord blood takes only a few minutes after the umbilical cord is cut.

These advantages have made cord blood a hot commodity in the medical and scientific world. In the past decade, doctors worldwide have performed about 1,500 cord blood transplants. And in the past five years, a handful of companies have been marketing cord blood banking to expectant mothers.

Cord Blood Registry is the largest of those companies. It enrolled nearly 9,000 clients last year, up from roughly 1,200 in 1996. And its rosters now total almost 19,000 clients.

Steve Grant, a company spokesman, estimates that between 20,000 and 30,000 families nationwide are storing their children's cord blood each year. He believes that number will grow as awareness about the option increases.

Joan Ross, director of women's services for Bon Secours, has seen the same trend and is responding to the growing interest shown by expectant parents.

"We had women calling, saying they had heard about it, saw it on the Internet or had a friend who did it," Ross said. "They were asking, 'What can you do for me?' We wanted to make the information available to them so they could make an informed decision."

Cord Blood Registry has agreed to provide Bon Secours with articles, brochures and research. And it will pay the health system \$100 for nursing education for every patient who enrolls in its program.

Patients who want to enroll in Cord Blood Registry's program can contact the company at least 45 days before the due date to make arrangements. But they're free to enroll in other companies' banking programs.

Bon Secours is also educating its nursing staff and obstetricians who use its hospitals about cord blood banking, collection techniques and ethical considerations.

“This is still something that families need to discuss with their own physicians,” Ross said. “Because in the end, for families with no known risks, it really is an insurance product.”

Dr. R. Nathan Slotnick, director of reproductive genetics and associate professor in maternal fetal medicine at Eastern Virginia Medical School, has helped dozens of families collect and store cord blood in the past several years.

He sees in it a potential cure for many diseases, including immune system disorders, leukemia and some other cancers. He looks forward to a day when cord blood is routinely collected. And he tells all his patients about the option.

But he is the first to point out the downsides. And he is adamant that expectant parents be told the pros and cons without bias and without pressure.

“I think it's a great, great thing,” said Slotnick, who is helping Bon Secours to educate its nurses and obstetricians. “But I have to tell you it's not for everybody.”

There is widespread agreement that a newborn's cord blood should be collected when a family needs it immediately, as in the case of a sick sibling. Most doctors also support its use for families with extensive medical histories of blood-borne diseases.

Nor do many people argue about the merits of donating cord blood - although the strained financial resources of most not-for-profit cord blood banks make donating difficult.

The controversy centers on families with no immediate need for cord blood or no real history of blood diseases.

“You're basically looking at an expensive insurance policy with small likelihood of panning out,” Slotnick said. “It's incumbent on us to say this is a wonderfully powerful tool. But this may not be a tool for you.”

Medical ethicists worry that companies may not be so forthcoming when marketing their services.

Companies, they argue, have a built-in incentive to emphasize the benefits of cord blood banking, tout its potential but unproven uses and downplay how unlikely it is that a family will ever need the blood.

“Companies are seeking money for something that for many diseases is of unknown efficacy,” said ODU's Eckenwiler. “No matter what, the company is going to benefit.”

Many questions remain unanswered, Eckenwiler said. No one knows whether cord blood works better than bone marrow, whether other advances will eliminate the future need for cord blood, or whether the blood contains genetic material that might have caused the disease.

Then, she points to these companies' Web sites - the pictures of healthy babies, testimonials about peace of mind, pitches about saving a child's life. Eckenwiler believes they are designed to prey on people's fears.

“The troubling thing is how information is provided and how it's presented,” Eckenwiler said. “Pressure is exerted in all sorts of ways. More often than not, it's very subtle.”

Leslie and Chris Edmonds had no family history of blood disorders.

The Portsmouth couple hadn't heard of cord blood banking, or given any serious thought to such precautions. They had two young children, who seemed perfectly healthy, and a third on the way.

Then, in December 1994, when Leslie Edmonds was seven months pregnant, they discovered that their 1-year-old daughter, Morgan, was seriously ill.

Bruises appeared all over Morgan's body. Just putting on socks could raise bruises on her legs.

She was diagnosed with thrombocytopenia, an extremely rare disease that causes a severe drop in the number of platelets, the small blood cells needed for clotting. Facing the possibility that any minor injury could cause serious bleeding, doctors decided she needed a bone marrow transplant.

But no one in the family was a good match, so Morgan's doctor suggested they turn to Slotnick to collect their third baby's cord blood stem cells.

So when Zachary was born in February 1995, his cord blood was collected and stored. It was later transplanted into Morgan, who is now in first grade and free of any signs of the disease.

"It's hard to believe she was ever even sick," Leslie Edmonds said. "We were fortunate. If it had happened three months later, we would have already had Zachary and thrown away the cord blood."

When the Edmondses had a fourth child two years ago, they banked his cord blood with Cord Blood Registry.

Leslie Edmonds would like to see a national organization for cord blood donation established. But short of that, she recommends that people store their children's cord blood if they can.

"You just never know," she said.

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**Caption:** [Color photo] STEVE EARLEY/The Virginian-Pilot Tim and Lisa Edwards walk on the beach with their son, Ian, 9 months old. When he was born, the couple decided to have the blood from the umbilical cord saved. THE LOCAL IMPACT Community discussions on cord blood banking Dr. R. Nathan Slotnick, director of reproductive genetics and associate professor in maternal fetal medicine at Eastern Virginia Medical School, will discuss cord blood banking and how it is used in today's medical treatments. The discussions will be at: 7 p.m. April 25 in the Price Auditorium at DePaul Medical Center in Norfolk. 7 p.m. April 27 in the Health Resource Center at Mary Immaculate Hospital in Newport News. To register, call 889-2273. ODDS The Edwardses knew cord blood treatments were experimental. They knew there was a slim chance - estimates varied from 1 in 1,000 to 1 in 200,000 - that they'd ever need it.

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