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Stem Cells in the Bank -- for What, It's Not Yet Known

Umbilical cord blood storage booms on parents' fears

By Alan Zarembo
 Times Staff Writer

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The courier arrived just after midnight with a bag of blood collected from a fresh umbilical cord.

Inside the laboratory at Family Cord Blood Services in Santa Monica, a worker siphoned off red cells, leaving a dilute mixture of stem cells — a personal supply for Olivia Michelle Boyd, born 15 hours earlier in Honolulu.

Her parents, Stephanie and Anthony Boyd, had agreed to pay the company \$1,265 to harvest the material and \$115 a year to preserve it in a stainless steel tank filled with liquid nitrogen.

Olivia was perfectly healthy. The stem cells were, the sales pitches suggested, biological insurance against disease.

"I'm unsure about the future," Stephanie Boyd said. "I know doing this is the best step."

In the still-experimental field of stem cells, the banking of umbilical cord blood has emerged as its biggest industry, driven by marketing claims that the blood could one day have the potential to cure ailments such as Parkinson's disease, paralysis and diabetes.

But there is little evidence that the promise of cord blood will ever be realized. The blood does indeed contain stem cells, but they are far different from the much-touted embryonic stem cells, which come from newly formed embryos and have the ability to become any tissue type.

That crucial distinction has been largely ignored in the marketing by more than two dozen companies around the world, most of them founded within the last five years. They have brought in hundreds of millions of dollars in harvesting and annual storage fees.

"I think the most exciting thing is that we don't know," said Dr. Charles Sims, a pathologist and co-founder of Family Cord Blood Services. "We can't say there won't be discoveries made."

The current uses of the stored stem cells are limited, and the private banks have little to show for their work so far.

The three largest cord blood businesses in the United States have collected more than 230,000 samples, generating at least \$300 million in revenue from anxious parents. Just a few dozen cord blood samples have been used, primarily for children with leukemia who could have been treated with equally effective alternatives.

At Family Cord Blood Services, just one sample has been used out of the more than 9,000 collected over the last eight years. The child died.

"This is purely a commercial business," said Dr. Eliane Gluckman, a French hematologist who performed the world's first successful cord blood transplant in 1988. It is "just for profit and not for benefit."

The European Group on Ethics in Science and New Technologies, which advises the European Union, concluded last year that "the legitimacy of commercial cord blood banks should be questioned as they sell a service, which has [currently] ... no real use regarding therapeutic options."

Italy enacted a ban on private banking in 2003 and other European countries have prohibited any company from profiting from cord blood.

The American Academy of Pediatrics also opposes private cord blood storage.

But despite the chorus of objections, the demand for private banking is growing.

Each burst of news articles on the promise of stem cells drives more parents to bank cord blood, if only to ensure that their children aren't deprived of a chance at a cure.

It is "a therapeutic option that not everybody is going to have," said Dr. Robert Hariri, president of LifebankUSA, a Cedar Knolls, N.J., company with more than 20,000 customers.

Boyd, now a mother of two, said: "It's one-twentieth the price of a car, and it will last a lot longer."

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ALZHEIMER'S CATCHES A MOTHER'S EYE

Boyd, 23, was a few months pregnant when the fliers for baby products and services started arriving. One day a brochure from a San Bruno, Calif., company called Cord Blood Registry appeared in her mailbox.

It explained how cord blood could be used to treat dozens of blood and immune system disorders and one day might be the cure for a range of other diseases.

One word stopped her: Alzheimer's. The degenerative brain disease runs in her family. There is no cure now, but maybe cord blood could help her child decades in the future, she thought.

"I can't imagine what they are going to do with stem cells 20 years from now," Boyd said.

She searched the Web and found a dozen companies that banked umbilical cord blood.

Her mother was skeptical until Boyd explained that stem cells were the future of medicine.

While her husband, an Army sergeant, was in Iraq, Boyd settled on Family Cord Blood Services. The company impressed her with a personalized letter and an informational DVD. It offered a free year of storage for military families.

"It just felt right," Boyd said later. "I went with my heart."

A week after she signed up, a collection kit arrived. It included a blood bag, labels, clamps, a shipping box and instructions for the doctor.

On May 16, a minute after Olivia was born, a doctor inserted a needle into the umbilical cord and let the blood drain into the bag. The sample was flown to Los Angeles and soon the name Boyd was entered into a logbook, below customers from New Haven, Conn., Jonesboro, Ark., Lima, Peru, and Mexico City.

Pregnant women everywhere are deluged with advertising for cord blood banking.

"What if I could help her survive a stroke?" reads one magazine advertisement for Cryo-Cell International Inc., based in Oldsmar, Fla.

Beneath the picture of a brown-eyed baby, the ad continues: "Imagine taking a step now, before she's born, that could turn the miracle of her life into a future medical miracle."

When the first cord blood company started in the early 1990s, nobody was thinking about using the cells to treat conditions such as Alzheimer's, diabetes or stroke. The businesses hoped to capitalize on the difficulty of finding suitable bone marrow donors.

Both bone marrow and cord blood contain a type of stem cell — known as a hematopoietic cell — that is responsible for generating all types of blood cells, including those responsible for the immune system.

Most commonly, hematopoietic cells are used in leukemia patients to rebuild bone marrow that is destroyed by chemotherapy. Other diseases they are used for include various forms of anemia, in which the marrow produces insufficient numbers of red blood cells.

Business was slow at first because such diseases are rare; it was difficult to persuade people to store blood.

Then came the stem cell craze.

It started when scientists isolated powerful cells from newly formed human embryos in 1998. The research spurred a moral and ethical debate over whether the potential for cures could justify the destruction of embryos. That prompted the Bush administration in 2001 to ban federal funding for certain types of research and California voters to pass a \$3-billion stem cell initiative last year.

The focus was embryonic stem cells, which have the proven ability to transform into any type of tissue — and only a vague resemblance to stem cells in cord blood.

That didn't seem to matter to people who bank.

"For the general public, they just hear the words 'stem cells,' " said Kaj Rydman, president of Family Cord Blood Services. "A large portion do it on blind faith."

Entrepreneurs are not waiting to find out if stem cells fulfill their promise.

Sales representatives visit doctors and stock their waiting rooms with brochures. The companies have begun to form alliances with obstetricians, paying them about \$150 for the minutes it takes to collect each sample.

"Unless it's captured in the first five minutes of life, it's gone forever," says a magazine ad for CorCell Inc. of Philadelphia.

Salespeople are waiting by the phone.

"Congratulations," said Joanie Mason at Family Cord Blood Services. "Is this your first baby?"

The pregnant woman calling from Texas was undecided about banking. It was a month before her due date — plenty of time to mull it over.

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NOT ALL STEM CELLS ARE THE SAME

Tens of thousands of parents-to-be have been calling the cord blood toll-free hotlines.

Consider figures provided by the three largest companies, which estimate their market share to be around 80%.

Cord Blood Registry: more than 90,000 customers.

ViaCord Inc. in Cambridge, Mass.: more than 60,000.

Cryo-Cell International: nearly 80,000.

Officials at the companies say business is at an all-time high.

The three companies each charge from \$1,110 to \$1,800 to collect and process the cord blood, plus \$115 to \$125 per year to store it.

Nobody knows whether a child will become sick or which scientific theories might result in cures.

For Clayton Frech and his wife, a movie actress, banking cord blood for their new son was as essential as buying an infant car seat.

"It's a pretty common and accepted practice in the circles we run in," said Frech, who runs a party-supply business in Los Angeles.

"People don't know exactly what we'll need this for," he said. "It seems better to play it safe and conservative and have some of these cells in storage."

The theory is that cord blood stem cells might be used one day to make nerve, liver and heart cells to treat a wide variety of degenerative diseases. Unblemished cells stored at birth would provide a storehouse of cures genetically matched to the donor.

But not all stem cells are the same.

Scientists have identified two basic types. Those found in embryos — embryonic stem cells — have the proven ability to transform into any cell. They are the source from which the body develops from a clump of undifferentiated cells into the complex collection of tissues that constitute a human being.

The other type, adult stem cells, are more specialized. They replace cells that are frequently destroyed, such as blood, hair and nasal cells.

Stem cells from umbilical cords are a type of adult stem cell.

As far as scientists know, the hematopoietic cells found in bone marrow and cord blood have just one power: the ability to transform into blood and immune cells.

Some scientists are researching the possibility that these cells can make other types of tissue.

The argument, however, has not been widely accepted, because the theory behind it remains unconvincing. Mature cells are the product of a series of biochemical reactions that turn certain genes on and off, triggering changes that are thought to be irreversible.

There is no evidence that they can return to their undifferentiated forms to head down a different path of development, said Dr. Curt Civin, a stem cell transplanter at Johns Hopkins University who has studied hematopoietic cells since the early 1980s.

Some adult stem cell researchers have another theory: Cord blood may contain a more primitive type of cell. Scientists can only speculate about such a cell. The idea that it exists comes from a few studies suggesting that something in bone marrow can transform into a variety of cell types.

One key experiment was reported in 2002 in the journal *Nature*. Dr. Catherine Verfaillie and a team of scientists at the University of Minnesota found that rare cells in bone marrow could be cultured in a laboratory and coaxed to produce bone, fat, muscle, liver, intestinal and neuron-like cells.

The same type of marrow cells, when injected into mice, in some cases appeared to become other kinds of cells — though not nerve cells, the key to curing many of the worst ailments.

The work was instantly controversial. Critics argue that if such transformations occur, they happen too rarely to be of therapeutic value.

In any case, evidence that such cells exist in cord blood is extremely weak. Verfaillie said her team has examined blood from more than 90 umbilical cords and failed to find them.

It is likely to be years, if not decades, before scientists understand the complex chain of reactions

that guide the transformation of cells.

Cord blood cures for diseases such as Parkinson's and diabetes are still a distant fantasy, Civin said: "We're nowhere near there yet. It is nowhere near certain that we will ever get there."

Dr. Joanne Kurtzberg, director of the pediatric stem cell transplant program at Duke University, whose work is often cited by cord blood banks, said "there is zero evidence" to support the advertising claims of such cures from cord blood.

Other therapies, Kurtzberg said, are just as likely to be developed by the time a child born today would contract many of the diseases advertised by the private banks.

"We don't even know if cord blood will last that long," she said.

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'A LIFE PRESERVER THAT DIDN'T FLOAT'

The companies advertise that even without considering future scientific breakthroughs, there are many reasons to privately bank stem cells now.

Many companies list dozens of blood, bone and immune diseases — most of them genetic disorders or forms of leukemia.

But the chances of patients using their own banked stem cells for those purposes are slim.

The problem is that transplanting the cells can reintroduce the same genetic defect that caused the disease in the first place. Using a child's own cord blood to treat leukemia is also a problem, since it could include cancer cells — or would simply regenerate the same immune system that already had failed to destroy them.

Tracey and Victor Dones of Levittown, N.Y., learned this lesson the hard way.

In July 2002, Tracey gave birth to a son, Anthony, and banked his cord blood. Four months later, doctors at North Shore University Hospital in Manhasset, N.Y., diagnosed him with osteopetrosis, a genetic defect that triggers a runaway increase in bone density.

He would die without a stem cell transplant, they told his parents.

Tracey Dones quickly responded that an exact genetic match was waiting in a freezer tank in Florida.

"How perfect can this be?" she recalled thinking.

The doctors, though, explained that the stored blood was useless.

The cells were "a life preserver that didn't float," Victor Dones likes to say.

What finally saved Anthony was a parallel system of cord blood storage known as public banking.

These banks are typically nonprofit. They don't charge parents for harvesting or storing the cells.

The public banks resemble blood banks, stockpiling donated cord blood and offering it to anybody in need of a transplant. The banks cover their costs by charging about \$20,000 for each sample. As part of an accepted medical procedure, the blood is usually covered by insurance.

Because cord blood can be used with a lower degree of genetic matching than bone marrow transplants, it is ideal for transplants from unrelated donors.

In May, Congress voted 431-1 to spend \$79 million to make searching easier by linking public cord blood banks in a national network.

There are about a dozen public banks scattered across the United States. Worldwide, such banks have provided cells for more than 5,000 cord blood transplants.

Their record far outstrips that of the private banks. The three biggest private banks have provided cells for 55 transplants, according to statistics they provided. In 49 of those cases, the cells went to a sibling, most often one already sick with leukemia or another disease when the blood was stored.

Privately stored cord blood was by no means the only treatment option. The siblings could have donated bone marrow, with the same odds of success. Or the children could have sought stem cells from an unrelated donor. There are 5.5 million bone marrow donors in a national registry, and more than 100,000 samples in public cord blood banks.

But the public banks lack one thing: cachet. Many parents believe private banks offer them the most security and control.

"It is analogous to private schools and public schools," said Stephen Grant, a vice president at Cord Blood Registry.

Dr. Robert Chow, the founder of Stemcyte Inc., which runs public and private banks in Arcadia and Taiwan, said the allure of private banking was too strong for many parents to resist.

"I understand why they do it," he said. "They will feel guilty if they don't."

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'THE RELIGION OF CORD BLOOD'

The emotional pull is irresistible for many parents.

"It's like a religion — the religion of cord blood," said Kenneth Worth, a Fullerton lawyer who has tried to fight cord blood companies but has struggled to find parents who feel wronged.

"People want to believe that it's true."

Reason alone is not enough to decide whether to bank.

Grant, of Cord Blood Registry, explained his strategy for handling roomfuls of skeptical doctors and scientists. He asks who would bank if the service were free. Most hands go up.

The message is clear: How could throwing something away be better than keeping it?

Sean Morrison, a stem cell biologist at the University of Michigan, had the chance to bank for free nine years ago. He sent his daughter's cells to a fellow researcher who was collecting samples.

"It's just like buying a lottery ticket," he said. "The chances of winning are extremely low, but that doesn't stop people from buying it."

When his second daughter was born two years later, storing the cells with his colleague was no longer an option. He knew what he had to do.

He signed up with Cord Blood Registry.

How could he justify banking for one and not the other?

The pressure to bank has grown as more parents choose to do it.

Annamarie Cummings of Crystal Lake, Ill., a Chicago suburb, said the issue had come up at neighborhood picnics. She said one mother regretted not banking. And lately there has been head-shaking talk about a child with leukemia whose parents apparently did not bank either.

Cummings said she and her husband, Bill, were ahead of the curve. They banked for their daughter in 1999 and for their twin sons two years later.

It is a lifetime commitment.

"We have decided to pay until all three of our children are 21 years of age," she said. "Then they can probably take it on from there."

From time to time, parents call Family Cord Blood Services hoping to come by and see the cells they banked, said Rydman, the company president.

There is nothing wrong. They just want to see.

Rydman tells them that they are free to look at the stainless steel tanks, but he explains that the samples are best left undisturbed.

The cells will keep for years and years and years, bathed in liquid nitrogen at 321 degrees below zero.

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