Cord Blood Banking Industry Flourishes

Cord Blood Banking Industry Geared to Expectant Mothers Flourishes Despite Practicality Issues

The Associated Press

NEW YORK April 11 — When Marla Dalton was expecting, she read the pregnancy magazines, picked up pamphlets at her doctor's office and logged on to mom-centric Web sites and chat rooms. In the process, she was inundated by marketing imploring her to privately store her twins' umbilical cord blood.

This is how it works: Cord blood is extracted from the umbilical cord and shipped to the private bank, where it is processed to separate the stem cells which are then deep frozen, typically in liquid nitrogen. Research has shown that cord blood stem cells can be used as an effective alternative to bone marrow in some cases.

The process got Dalton thinking. Was this really a once-in-a-lifetime opportunity to capture blood rich with stem cells that could potentially save the twins or a family member from serious diseases and conditions? Was it was worth the collection and processing fees, many ranging from $1,000 to $1,740 per child? Plus a likely $95 annual storage fee.

"It was really stressful. The marketing makes you feel guilty," the 41-year old engineer said. "There is this feeling that if you don't do it, you are not doing something to save your child's life."

The marketing has proved to be effective. The private blood banking industry is expanding although many medical experts criticize the companies for exploiting parents' paranoia. Many doctors advise healthy families not to succumb to promotions because the likelihood of ever using the blood is rare, future medical uses for it are uncertain and storage standards can be lacking.

Still, private companies report double-digit increases in the number of units of blood they store. There are at least 27 storage companies, up from about 12 three years ago.

Cord Blood Registry said the number of units it stores has risen 40 percent to 50 percent in each of the last few years and now totals about 60,000. CorCell Inc. said that in one year, its client base grew 100 percent and that it now stores over 8,000 units. LifebankUSA said it adds thousands of new clients annually, storing about 20,000 units.

"Blood banking is a speculative investment in the future," said Dr. Robert J. Hariri, president of Celgene Cellular Therapeutics, which runs LifeBankUSA. "But you are protected against some diseases now and you bank because stem cells are a medical resource for the future."

One magazine ad reads, "$899 can ensure a lifetime of precious memories," while another insists cord blood storage is "added security for a changing world."

"Umbilical cord blood could save a life if you preserve it at birth with Viacord," says one of that company's booklets. On the Cord Blood Registry site, TV personality Leeza Gibbons says, "your baby's cord blood is worth saving" and "every day there seems to be another use for cord blood stem cells."

What the storage firms' promotions don't say is that the vast majority about 3,500 of cord blood stem cell transplants have been done using cells from unrelated donors from public banks. About 300 transplants have involved sibling donors while 14 have been done using a child's own cells, said Dr. John Wagner, Scientific Director of Clinical Research of the Blood and Marrow Transplant Program and Stem Cell Institute at the University of Minnesota.

Wagner doesn't believe healthy families should privately store children's stem cells. But even he was moved by the marketing when his wife was pregnant.

"It really makes you think you're a bad parent if you don't do this," he said.

Wagner thinks the companies' marketing messages have softened in seven years since his twins were born. But much is missing or misleading in Web sites, ads and marketing materials. For example, the companies don't say that the American Academy of Pediatrics says that in most cases private storage of cord blood is unwise.

The academy says no accurate estimates exist of the likelihood that children will need their own stored cells, but estimates range from 1 in 1,000 to 1 in 200,000. In seven years of operation, CorCell, for example, has never shipped a unit of blood.

The Web site for StemCyte, which takes public cord blood donations from hospitals in Southern California, mentions the academy's opinion and statistic. However, its division which charges families to privately bank blood, Cord Blood Family Trust, does not.

Some Web sites list the various conditions that have been treated with cord blood stem cell transplants, including genetic diseases and leukemia. But if a child has a genetic disease, his or her own cord blood would be useless in treating it because the cells are also infected. And doctors said that if a child gets leukemia at a young age, a cord blood transplant wouldn't be done for fear the blood might also have the condition. However, in either case, a sibling's blood might help.

Tracey Dones learned the limitations of private blood banking the hard way. When her son Anthony was four months old he was diagnosed with osteopetrosis, a rare genetic bone disease. She thought the cord blood she stored would save his life but because the stem cells contained the disease, it was useless.

"I feel like I was misled," Dones said. "I was under impression if my kid got sick the cord blood would save him."

Anthony's life was saved by a non-related donor.

Doctors say that if parents donate their children's cord blood to a public bank, there is a high probability it will be used. There are only about 20 public banks in the country but they can only work with a limited number of hospitals because receiving and processing the donations is expensive. A bill introduced in the Senate last October would expand public cord blood banking.

Dr. Joanne Kurtzberg, director of the pediatric bone marrow and stem cell transplant program at Duke University Medical Center, questions whether it is appropriate for private blood banks to bring up potential future uses such as diabetes or arthritis in marketing materials, as many do. She said evolving technology may mean that other types of cells might be as good as cord blood stem cells for transplants.

"None of these companies are saying that if you don't save your child's cord blood, there are other alternatives if a child gets sick," said Kurtzberg.

Cord Blood Registry founder and vice president Stephen Grant conceded that some might see the marketing as fear mongering but he insisted the charge is unfair.

"I don't think we can convey the benefits of the service without conveying the reality that a child might get sick," Grant said. "We have to talk about the prospect of leukemia or transplant and you might say that is a scare tactic, but to us it is reality."

He doesn't want parents who don't store cord blood to feel guilt.

"It is up to every person to decide the risk to reward ratio," Grant said. "But I buy insurance for things less likely to happen."

Doctors are also concerned about the conditions under which the companies store cord blood. Both Wagner and Kurtzberg say standards at private banks don't match those of public banks, and that it's difficult for parents to know if the blood is being properly stored and whether it will be viable if needed.

Another problem is that many patients needing cord blood are adults, who, because of their size, might need more blood than it's possible to capture from an umbilical cord. Kurtzberg said she has had 12 occasions to use privately stored blood and that in about half the cases there wasn't enough to transplant. That's another reason she doesn't believes marketers shouldn't be touting the future uses of the blood.

Doctors aren't alone in their concerns. Engineer Robert Vago said he left Cyro-Cell International Inc. in 2000 because of his concerns over the reliability of the company's freezing procedure. "From my point of view the Food and Drug Administration should be regulating this industry," he said.

Cyro-Cell declined comment.

Cord blood banks must register with the FDA and although there are plans for the agency to inspect the companies, there is no timetable for when that will happen. Some private banks have been accredited by the American Association of Blood Banks.

Grants agrees it is difficult for parents to distinguish between banks. "It really is caveat emptor."

He suggests parents ask about companies' track records and profitability. CorCell Inc. president and chief executive Marcia Laleman recommends asking about accreditation, storage facilities and transportation procedures.

Marla Dalton said her inability to distinguish between quality controls at the different banks played a role in her decision not to store her children's' cord blood.

Carolyn Kohn understands the benefits of privately storing cord blood in a way most mothers can't. She stored her son Brady's cord blood because her husband is adopted and thought it might come in handy one day. Kohn was right.

Brady's own stem cells were transplanted back into him after he was diagnosed with aplastic anemia when he was 2. The transplant worked although Brady died from an infection.

Kohn became an advocate for cord blood research and storage, both private and public. She started the Brady Kohn Foundation which educates people about bone marrow transplants and cord blood, raises money for research and even delivers cord blood to public banks when moms decided not to store privately.

She privately banked her second son's cord blood.

"I think it a small price to pay," said Kohn. Yet, she understands that some people may not be able to afford the expense.

But, Kohn said, "whatever you do, just don't throw the cord blood away."

On the Net:

www.bradykohnfoundation.org