

# Children Saving Children

By Mary Dixon Lebeau

**S**ure, we can quote facts and rehash figures. But sometimes the best way to understand cord blood banking is to hear the story of one family who chose to bank their baby's cord blood... and who now have a healthy son because of it.

When her son's high fever persisted despite antibiotics, Susan Jarvis-Orr of Mesa, AZ, did what any mother would do: she took young Brandyn — just weeks past his second birthday — to the doctor for further testing. She didn't know about the ordeal that her little boy would be dealing with, or that another son, born years later, would give doctors the key to save Brandyn's life.

"Tests were ordered, the fever wasn't typical and I knew something was wrong, but I never imagined what we were facing," Jarvis-Orr says. The young mother, 6 months pregnant with her second child, listened intently to the parade of doctors, trying to absorb what was happening as she heard terms like "bone marrow testing" and "hospitalization" being thrown around.

"They were talking about my little boy," Jarvis-Orr remembers. "I just never dreamed..." Despite all the confusion, Jarvis-Orr does remember one thing clearly. "It was Dr. Terry Wood who first said the word 'leukemia,'" she says.

After waiting "the most painful 24

hours I ever went through," Jarvis-Orr heard the official diagnosis. Tests confirmed what Dr. Wood suspected: Brandyn had acute lymphoblastic leukemia (ALL).

Dr. Wood was also the first one to mention a possible cure for Brandyn. "Dr. Wood approached me about the possibility of using the cord blood cells of the baby I was carrying to help Brandyn," she says. He explained that the newborn stem cells in the baby's umbilical cord blood might

be able to save her older son. "I had never heard about cord blood banking before Brandyn was ill. I certainly would have banked his cord blood if I had known about it."

Brandyn was in his third month of what would become a 3-year chemotherapy regimen when baby brother Kaeyln was born. Told that siblings had a 50% chance of being a suitable blood match (some researchers put this number





as high as 75%), the Orrs immediately banked Kaeyln's cord blood.

Fortunately, after the painful chemotherapy, Brandyn's leukemia went into remission. The family had a breather — at least momentarily. Brandyn was back at home with his parents and Kaeyln, and his mother had given birth to a third son, baby Devyn. Even though they thought Brandyn was out of danger, the Orrs decided to bank Devyn's cord blood as

well. "By that time, I was educated. I had no doubt that cord blood banking was the smart thing to do," Jarvis-Orr says.

#### **Setbacks and Success**

Unfortunately, the remission was short-lived. "I was told that only 8% of the leukemia cases come back after such a remission," says Jarvis-Orr. But Brandyn's leukemia did come back, and only 6 months after he went into remission.

The family was enjoying a respite in Florida when the symptoms returned. Brandyn, by then an active 5 1/2 year old, complained of aches, pains and weariness, showing his parents some unexplainable bruises. "We immediately took him to a clinic and had blood tests done," Jarvis-Orr says.

Brandyn had indeed suffered a relapse and was in need of help. "We really had no idea what we were in for. The most

challenging experience of our lives was still to come," his mother says.

The family returned home to Arizona and Brandyn was treated at the University Medical Center in Tucson. He received another round of intensive chemotherapy and radiation to his head and spine. "Brandyn was always so brave through all the treatments and testing," Jarvis-Orr says.

Again, the topic of a stem cell transplant was discussed. This time, the Orrs had something they hoped they could bank on: the cord blood of Brandyn's two younger brothers. Jarvis-Orr tried to focus on that number — 25% — as she prayed that the banked cord blood could save her oldest son.

The first results were discouraging: Kaelyn was not a match. But remarkably, the cord blood cells banked after the birth

all hoped and prayed for each other, but many of them weren't going to get one."

### Facts and Figures

What is cord blood, anyway? "Cord blood is the blood that remains in the umbilical cord after a baby is born. It is a rich source of stem cells," says Dr. Charles A. Sims, co-founder and medical director of Family Cord Blood Services in Santa Monica.

"Stem cells are unspecified blood cells, genetically unique to a child and family, that produce all other blood cells, including platelets, red and white blood cells and the immune system," Sims says. "The term 'cord blood banking' refers to storing or banking the baby's cord blood [stem cells] for future medical use."

How can these cells be used? "The

expanding throughout the world to find ways to utilize this very rich biological resource."

"To date, there [have] been over 4,000 cord blood stem cell transplants worldwide," Sears says. "Current research shows promising results in repairing damaged heart tissue after a stroke or traumatic injury, repairing degenerative brain diseases like Parkinson's and Alzheimer's, treating immune diseases like multiple sclerosis and diabetes, repairing joint damage from arthritic conditions, and improving eyesight in degenerative visual conditions."

If a family wants to bank their child's cord blood, it's a fairly simple procedure. "When a family decides to bank their cord blood, they arrange to have a collection kit sent to them from a private company at least a few weeks before their due date," explains Sears. "At the time of birth, the cord blood is drained from the remaining umbilical cord and placenta, placed into a sterile storage bag and shipped overnight to the storage facility, or 'bank,' of choice." There, the stem cells are separated from the cord blood, placed into vials, and then frozen in liquid nitrogen in a large tank for long-term storage.

"More and more parents are making the decision to store their baby's cord blood, not only for present applications, but also for the future potential uses of stem cells, which might include treatment of certain diseases," says Sims.

But the window of opportunity is only opened momentarily. "Deciding to bank the cord blood is a once-in-a-lifetime source of potential 'biological insurance' which must be done at the time of birth," Sims adds.

### Bank Notes of Interest

There are two different types of cord blood banks. Private banks, such as LifeBankUSA and Family Cord Blood Services, work like financial institutions in that whatever you deposit remains there for your own personal use. "Private banks provide families the security in knowing that their own cord blood will be available if the need arises," says Sims.

The other types of banks are for public donation. "Donating cord blood to a public bank is a generous step," says Sears. "The stem cells will be used by the first

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of little Devyn just 4 1/2 months earlier were. Jarvis-Orr says, "We were so glad we had saved Devyn's cord blood, as the doctors weren't sure they could get enough bone marrow from a baby that young." Instead, their oldest son received his transplant, and their youngest did not have to go through a painful donor procedure.

"80% of the battle is having that match," Jarvis-Orr adds. "Thank God I didn't have to go through searching the donor registries. I saw so many patients in the transplant ward who suffered through more complications than Brandyn because they didn't have matching stem cells from their own family."

Harder still was meeting people for whom a transplant would never happen, Jarvis-Orr says. "There were people right there in Tucson waiting for a match. We

principal reason, initially, was the clinical need to have these cells to perform bone marrow transplants," says Dr. Robert Hariri, president of LifeBankUSA in Summit, NJ. "Through the years, we've learned they're useful for other things as well." He adds, "Stem cells retain the ability to mature into specialized cells."

"Historically stem cells have only been used in transplantation for certain hematologic diseases and malignancies that have failed chemotherapy," says Dr. Bob Sears, a California-based pediatrician, father of three and co-author of *The Baby Book*. "But now there is much more to the decision [to bank your child's cord blood]. It's no longer just about leukemia. The medical community has recognized that stem cells can be used to treat a variety of health conditions, and research is

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person in need who matches the cells. The problem is, very few public banks exist. Most families who want to donate their cord blood are unable to do so because access to public banks is difficult. Private banking, on the other hand, is easily arranged and assures the donor’s family will have these... cells available should the need ever arise.”

“In my opinion, a baby’s cord blood is valuable and should be collected and stored,” says Sears. “Parents who choose not to store in a private bank should consider donating their cord blood to a public bank, if available in their area, so their baby’s stem cells can be used by another person who may need it. This is a biological resource that should not be discarded.”

Brandyn’s mom agrees with Sears. “People need to be aware that they can save someone’s life with this one simple action,” she says. “Don’t throw away that possibility.”

#### **Stronger Every Day**

Today, Brandyn Orr is a healthy, happy fourth grader at the Arizona Virtual Academy. “He’s a really good kid,” Jarvis-Orr says. And for once, those aren’t just the words of a proud mom. The entire community is proud of Brandyn, who recently received a Young Hero Award for saving a woman’s life. He had been in a local Walgreens and noticed the woman was choking. Thinking quickly, Brandyn applied the Heimlich maneuver, which he had learned in a babysitting class.

Brave? Sure. It’s no surprise, though. After all, saving lives runs in the family. ●

*About the author: Mary Lebeau is an ePregnancy contributing editor and a New Jersey mother of five.*