

COLUMBIA MISSOURIAN

Family seeks help in China through cord blood stem cell transplant

By [Samantha Clemens](#)

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WARDSVILLE — A wide-open smile crosses the face of Luke Pickett, exposing a new tooth poking through his gums. It popped through a few days ago. One of Luke's physical therapists gives the 18-month-old help standing up. Securely held, Luke wobbles his head, which follows his swaying body, before he manages to hold it steady and upright for three seconds. This is an improvement for the giggly boy in a "Finding Nemo" swim diaper, who is at his three-month evaluation of aquatic therapy for cerebral palsy.

Luke's parents, Cheryl and Clint Pickett of Wardsville, south of Jefferson City, learned in September 2007 that their son has spastic quadriplegic cerebral palsy, a neurological disorder that, for Luke, creates high muscle tone in his extremities and low muscle tone in his neck and torso, causing gross motor delays. In Luke's case, his verbal skills are also affected, and aside from his ongoing laugh, he does not talk.

"At four to five months, he wasn't holding his head up or grabbing toys," Clint Pickett said. "We knew he wasn't developing right."

For the past year, Luke's parents have researched and tried alternative therapies for their son. Now, Luke is in China with his father for a donated umbilical cord blood stem cell transplant. The hope is that the stem cells will "help rejuvenate Luke's damaged cells," Clint Pickett said, possibly improving Luke's muscle tone and verbal skills.

Although cord blood stem cell transplants are available for about 70 conditions in the U.S., cerebral palsy and other conditions have not been approved by the Federal Drug Administration for the treatment. Since May, the Picketts have been raising money for the travel and transplant expenses to get to China, which will cost about \$30,000. After six events, including a golf tournament, a silent auction and a 5K run, family, friends and the community have raised enough money to meet the financial demands of the procedure. They've also given emotional support to the family by offering prayers and sending cards that have stacked up on the Picketts' countertop.

At the 5K fundraiser on Aug. 30 at Stephens Lake Park, runners crossed the finish line wearing T-shirts with Luke's smiling face printed on the front while Cheryl Pickett talked about the help her family has received.

"The response has been overwhelming. I never thought we'd raise \$30,000," the stay-at-home mom said with tears. "You always hear about the economy. We're hurting, too. We're a single-income family, and people who have never met us are sending money."

Luke and his father left for China on Oct. 4 and will stay until Nov. 8 at Chengyang People's Hospital in Qingdao in northeast China. Cheryl Pickett, who is pregnant with twins, is staying home to care for their 3-year-old son, Cody.

Luke is receiving seven treatments of donated cord blood, two intravenous and five lumbar injections. Lumbar injections put the cord blood stem cells into the space that cushions the spinal cord. Technically, the donated cord blood stem cells are adult stem cells, not embryonic.

Cord blood transplants

Cord blood is collected from the umbilical cord and placenta after birth, causing no harm to the mother or child.

Since the first successful cord blood transplant in 1988 in France, research on cord blood and its potential has expanded. To date, more than 12,000 cord blood transplants have been performed worldwide, according to CordBloodAwareness.org. Cord blood stem cell transplants are either autologous, treating the patient with his or her own cord blood, or allogeneic, treating the patient with donated cord blood from a related or unrelated person.

Beike Biotech, a company based in China, supplies the stem cells for Luke's treatment. The cord blood is obtained from the Chinese government after it has been collected from umbilical cords in Chinese hospitals. Kirshner Ross-Vaden, a registered nurse and vice president of the foreign patient division of Beike Biotech, said the company has about 40 patients each month who, like Luke, travel to China to receive the treatment.

Ross-Vaden said undergoing stem cell procedures while young gives the patient a better chance for damaged cells to be recovered.

The brain is more moldable the younger the patient is, Ross-Vaden said. "If you get in soon enough, you can recover those cells and decrease the level of injury for the patient."

Because cord blood stem cell transplants are unavailable for cerebral palsy in the U.S., the Picketts and others have little choice but to travel abroad for immediate treatment possibilities, which concerns some in the field.

"The data isn't there at all for cord blood with cerebral palsy," said Mindy Aisen, a physician and director and chief executive officer of the Cerebral Palsy International Research Foundation.

"I would never advise someone to go to China, period, period, period. You're injecting a mixture of things when injecting cord blood intravenously. It's not clear if anything is crossing the blood-brain barrier," Aisen said, referring to a barrier of cells that lines the walls of blood vessels in the brain, which can block substances from passing.

The Picketts said they chose China over other countries that offer the procedure such as Costa Rica because they heard positive outcomes from other parents on online support groups. Although they were told by their doctors there is no definitive evidence that the treatment works and by Beike Biotech that the company offers no guarantees, the stories of other parents seeing improvements in their children is enough reason to take a chance.

"We're not hoping for a miracle," Cheryl Pickett said. "Any improvement would be better. If it helps to reduce his spasticity or it gets rid of his twitches that he has at nighttime, maybe he's able to eat with his hands or hold his bottle, or say, 'Mommy.' I think any parent out there, whether you agree or disagree with stem cell treatment, all parents would agree that you'd do anything for your child."

Private family banking vs. public donations

Banking umbilical cord blood publicly, privately or not at all leaves parents with a number of questions to consider. Is there a chance the child will develop some condition in which he or she could need the cord blood for treatment? Is there a chance a sibling or relative could use the child's cord blood as a possible treatment? Should the child's cord blood go into a public donation bank, so the greater population has access to it?

"If I would have known then what I know now, we would have banked (Luke's cord blood)," Cheryl Pickett said.

If Luke had his cord blood privately banked, the Picketts would have tried to get him into a clinical trial in the U.S. that would have used his own cord blood for a transplant.

"You don't ever think anything is going to be wrong with your kids. But (with) these babies, we will definitely bank their cord blood," Cheryl Pickett said, patting her pregnant stomach. "You just never know, down the line, five years or 10 years, it might be something Luke could use."

Initial private banking of a child's cord blood for future possible autologous or allogeneic purposes can cost from \$1,000 to \$2,000 for collection and up to \$175 per year for annual storage costs, according to ParentsGuideCordBlood.com.

Public cord blood banks, however, like the St. Louis Cord Blood Bank, accept free cord blood donations from the surrounding area to increase its availability to the public.

"Our goal is to make as many units available to the public," said Kathy Mueckl, nurse coordinator for the St. Louis Cord Blood Bank.

The amount of cord blood collected after birth varies depending on how much is left inside the umbilical cord and placenta. Typically, a teaspoon to 8 ounces is available. Whether the amount of blood is enough to merit saving depends on whether one plans to donate it or bank it privately. To donate it, banks require a certain amount of cord blood; many private banks will accept any quantity, Mueckl said.

For the St. Louis Cord Blood Bank, which says it is the second most active public cord blood bank in the world, at least 2 ounces of cord blood are needed. After the donation, the cord blood is tested to make sure it is safe for a transplant, and then it is stored until it is needed. At the St. Louis Cord Blood Bank, 25 percent of donated cord blood can be used in transplants. The rest is used for research or is discarded.

A growing number of donations has increased the availability of cord blood for possible treatment of diseases such as Hodgkin's lymphoma, Krabbe disease and non-Hodgkin's lymphoma.

The St. Louis Cord Blood Bank expects about 10,000 donations for 2008, up from 8,312 donations in 2007, Mueckl said.

Those donations have the potential to improve — in some cases, even save — lives.

The Picketts are hopeful. "We try to live a normal life as possible," Cheryl Pickett said. "Just because Luke has cerebral palsy doesn't mean we have to stop living our life as a normal family."

After the family of four, going on six, finished dinner on a September evening, they headed out to the front porch. Cheryl pushed Cody in a swing while Clint held Luke, kissing him on his head. Mia, their chocolate lab, could be heard barking in her kennel back around the house. Clint passed Luke off to Cheryl while he and Cody played fetch with Mia for a little while. Later, during bath time, the two brothers were side-by-side while Mom and Dad washed their hair. Cody was occupied playing with one of his many trucks, and Luke was laughing next to him, sitting in a chair that propped him up.

"We're good parents and we'll do whatever we can for him," Cheryl Pickett said. "I definitely believe God has helped us and brought stuff into light for us, helping us find out about stem cells."

"We decided to have one more baby and he gave us two, because maybe in 10 years Luke might be able to use two cord bloods," she said, wiping tears from her face. "I don't know, but I like to believe that."

For more information:

[International Cord Blood Society](#)

[The National Institute of Health resource for stem cells](#)

[Cord Blood Registry](#)

[Cord Blood Awareness](#)

[StemCellsChina.com](#)

[BeikeBiotech.com](#)

[Bone Marrow and Cord Blood Donation Transplantation](#)

[International Society for Stem Cell Research](#)

[White House release](#): President Bush signs "Stem cell therapeutic and research act of 2005"

To see the Picketts' blog, click [here](#).

Clint Pickett's blog from China can be found [here](#).