

Tucson Citizen

Parents credit cord blood transplant with healing daughter's brain

Transplant study may offer hope for people with cerebral palsy

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Published: 01.09.2009

The cheery toddler runs down the hall, waving her arms above her head as she reaches her target.

Chloe Levine, 2 1/2 , jumps into the arms of her dad, Ryan Levine, and the two share a snuggle.

"Running like that with two arms up in the air was impossible before," says Chloe's mom, Jenny Levine, 32.

Chloe, who has cerebral palsy, was transplanted with her own stem cells on May 27, 2008, as part of a study at Duke University.

The cells were collected at birth from Chloe's umbilical cord and frozen, months before her parents knew there was anything wrong with their precious daughter. They were stored in Tucson at Cord Blood Registry, near Tucson International Airport.

Scientists debate whether stem cells can help children such as Chloe, or if the improvement in motor skills would have occurred anyway.

But the Levines believe Chloe's improvement since the transplant is nothing short of a miracle.

"She's normal now," says Jenny Levine, as her daughter colors a picture of Elmo with a bright pink crayon. "She's doing everything a normal 2-year-old does."

When Chloe's parents were expecting her sister, Shayla, now 5, they investigated the possibility of storing her cord blood. But they could not afford the initial \$2,000 investment at the time.

When pregnant with Chloe, Jenny Levine was determined to store her second child's cord blood.

"It was one of the first things we decided," she said. "There have always been two things in life that scare me the most, cancer and car accidents. We looked at it as a life insurance policy."

The family was living in Pinetop when Chloe was born. They now live in Denver, where Jenny stays home with the girls and Ryan, 34, is in the cell phone business.

Jenny had a difficult pregnancy, and Chloe was born a month early.

"But every indication was that she was just fine," she said.

At 9 months, the couple worried that Chloe could not hold her bottle.

"Her little right hand was always in a tight fist," Jenny recalled.

They took her to a pediatrician, who didn't seem concerned.

"But my instincts told me something was not right," Jenny said.

At her year check-up, Jenny told the pediatrician she was not crawling, and didn't put weight on her right side. A brain scan showed Chloe had hemiplegic cerebral palsy, and that she suffered a stroke in utero, probably early in pregnancy. Some of Chloe's brain tissue, Jenny said, stopped developing.

The family consulted a Phoenix neurologist. "I told him we had cord blood stored, and asked if there was any possible use," Jenny recalled.

"He said, 'No, it won't benefit you.' "

They were told Chloe would need physical, occupational and speech therapy throughout her childhood. "We trusted what he had to say, accepted what we had to do and we went home," Jenny said.

In December 2007, the family heard about Dallas Hextell, a Sacramento boy with cerebral palsy who had been infused with his own stem cells as part of the study at Duke, and was responding well.

"I immediately got in contact with Duke," Jenny said. The hope, she said, is that the infusion of stem cells could cause brain tissue to regenerate, improving Chloe's mobility.

"They will not guarantee you anything," Jenny said, "The worst that can happen is nothing happens."

"We didn't have any expectations, but we wanted to know we had tried everything," Ryan said.

Last May, Chloe's stored stem cells were tested and sent to Duke, where she was infused through an IV in her arm. Her parents say they saw a nearly immediate change.

"She woke up the next day and she was a different kid," Jenny said.

"Two days later, in the car, she said her first word, 'Coco,' her nickname."

At her grandparents' house a couple of days after infusion, Chloe was able to use her right foot to push the pedal of a toy tractor, something she had not been able to do before.

The family will return to Duke in May or June for evaluation. Dr. Joanne Kurtzberg, the Duke transplant specialist who treated Chloe, is not granting media interviews, and the study is still in its early stages. But the Levines believe the transplant is saving their daughter.

"It has been life-changing in every aspect," Jenny said. "She no longer needs speech therapy, and we are seeing improvement every day. It's amazing."

AAP cord blood recommendations

When deciding whether to bank your baby's cord blood, discuss the options with your obstetrician. Here is what to consider when deciding which company to select, according to the American Academy of Pediatrics:

- Does the company bank for personal and family use?
- Institutional Review Board-approved protocols should be in place, including annual disclosure of the financial interest and potential conflicts of interest.
- Financial viability and stability of the company should be considered.
- Physician should disclose any potential conflict of interest.
- Company should have an informed consent process in place and require the parent to sign an informed consent.
- Cord blood banks should comply with national accreditation standards developed by the Foundation for the Accreditation of Cellular Therapy, the U.S. Food and Drug Administration, the Federal Trade Commission and similar state agencies.

ADDITIONAL INFORMATION