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Stem cells: Small wonders

Chloe Levine, 2, jumps on her bed recently, a simple action that she could barely do a year ago with cerebral palsy that affected her right side. An experimental stem-cell procedure, using her own stem cells, helped improve the toddler s mobility. (Joe Amon, The Denver Post)

With a nearly paralyzed right side, Chloe Levine was diagnosed with cerebral palsy at 1. A year later, she can say her nickname and is walking normally and jumping on beds.

By Michael Booth
The Denver Post

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With one simple word from the back seat of a car cruising between North Carolina and New York, 2-year-old Chloe Levine signaled a great leap forward.

"Coco," the Colorado toddler said, uttering her nickname for the first time.

Those two syllables marked a milestone in stem-cell therapy, helping prove that infusing a baby with its own stem cells can repair a brain ravaged by cerebral palsy.

Before a one-time treatment at Duke University in May, Chloe had speech problems, and the right side of her body was nearly paralyzed. Now she's jumping off beds, applying doll barrettes with her right hand and learning new words every day. The Duke experiments expand again the remarkable range of bodily failures that stem cells can repair.

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But even more, the word "Coco" made a mom and dad ecstatic. For Jenny Levine, Chloe's recovery is equal parts science, magic and miracle.

"It's like somebody unlocked the door on her personality, and it just charged through," said Jenny, as Chloe and her 4-year-old sister, Shayla, thumped and squealed from bed to floor in a room upstairs. In between jumps, Chloe used her relaxed right hand — which for two straight years had been balled up in a nearly useless fist — to turn up the volume on a "Barney" episode.

Just two days after Chloe's stem-cell infusion, "things started happening that she could never do before, and we finally let ourselves stop thinking it was a coincidence," Levine said.

"It's exciting," said Dr. Brian Freed, director of the University of Colorado Cord Blood Bank at the University of Colorado Denver School of Medicine. When the treatment works, the Duke study has been gratifying to parents, Freed said, because "this one is a bit more dramatic" than other stem-cell treatments. "You can see the benefits."

Cord-blood banking debate

The Levines' case is also both a coup and a question mark for the cord-blood banking world, where families may publicly or privately store umbilical-cord cells at birth for use to treat disease.

The Levines used private banking, where they paid an extraction fee and annual retainer to store Chloe's umbilical cells, without knowing she would actually need them two years later.

In public banking, like at the University of Colorado, families donate their new baby's cells for free, for the use of others.

The Duke cases "add to the controversy about banking their own cord blood or donating it," Freed said. "This would argue in favor of private banking for your own use. But in most cases, it's very rare that cord blood would be used for your own child."

The Levines were as shocked as anyone that a decision based on nothing more than generic motherly anxiety ended up transforming Chloe's life.

Levine had considered banking Shayla's cord blood, but was discouraged by the $2,000 upfront cost and $125 in annual storage fees. Her mom worries persisted, though.

"Two things I've always worried about for my family are car accidents and cancer," Levine said. "You can get car insurance and health insurance for those.

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But cord blood is another kind of insurance because the stem cells can help in car accidents, cancer and a lot of other problems."

For Chloe, the Levines went ahead and spent the money.

Chloe's diagnosis

Baby Chloe seemed to be developing normally until about nine months after her birth, when the family noticed she was holding bottles and other objects only in her left hand. When it came time to try crawling, Chloe created an odd bouncing movement from a sitting position. She moved her left leg out in front, and used the weaker right leg as a prop.

Their Denver pediatrician said to wait and see. By a year, Chloe clearly wasn't using her right side equally and showed other possible signs of a stroke. She would bump into people and walls, as if she had no peripheral vision on her right side.

A brain scan uncovered evidence of a random in utero stroke on the left side of Chloe's head, affecting her right side.

The stroke caused cerebral palsy, a broad term covering forms of brain damage that affect motor control but not mental functioning. Levine said she felt relief, in a sense, that Chloe's problems weren't from a brain tumor.

The good news about cerebral palsy is that it's not progressive — even if patients need years of physical therapy, they will not get worse.

The bad news, which is frankly stated in the Wikipedia entry, is: "There is no known cure for CP."

But for some lucky patients, that "is" may change to a "was."

The Levines were buckling down for years of physical and occupational therapy for Chloe, already a sunny and active child. Then Levine's sister-in-law sent an e-mailed story about an experimental therapy at Duke, using a child's banked cord-blood stem cells to treat cerebral palsy.

Stem cells work fast

This is where the scientific miracles begin, in Levine's view. The stem cells from the cord blood get to the child's brain through an IV into the arm — no matter where in the body the damaged tissue sits, the stem cells have their own road map to get there.

Once there, scientists still aren't sure how the stem cells work to fix cerebral palsy. Some think the cells may be able to rebuild brain tissue itself. Others think there is more evidence that the stem cells repair blood vessels and flow damaged by a stroke, bringing crucial blood that in turn repairs brain tissue.

Either way, doctors told the Levines, expect fast results if the new therapy was meant to help Chloe. They drove from Duke to Jenny Levine's family in New York, and that's when Chloe dropped her little "Coco" bomb.

The Levines immediately noticed Chloe's clenched right hand relaxing, and instead of dragging her right leg, she began walking normally.

Chloe can now raise both arms over her head and is eating and picking things up with both hands. Her therapy is down to once a month to check foot tendons for continued mobility.

"I still see new improvement every day," Levine said. She believes most of the effects of the cerebral palsy are gone and that any remaining tightness in Chloe's body will disappear with time and therapy.

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"I've never seen anything turn around this fast," said Dottie Waldo, Chloe's physical therapist in northern Arizona, where the family lived before the stem-cell procedure.

Waldo saw Chloe a month ago and was shocked at the recovery of movement in her hands and arms. "I'm a believer," Waldo said. "I think it was the right thing to do, and I hope it helps a lot of kids in the future."

Duke's doctors were not available to comment on the procedure or how many of the 30 children treated with their own cord blood have seen improvements such as Chloe's.

The Cord Blood Registry, a major cord-blood bank that has worked with Duke on many of the cerebral palsy cases, said the official stance is that there is "anecdotal evidence of substantial improvement" from some of the patients.

Back home in Highlands Ranch, Levine still smiles at the puzzle pieces of Chloe's recovery. A mother's instinct to bank cord blood; a sister-in-law who just happened to hear about an obscure experiment; stem cells that find their way home.

"Chloe was put here to teach the medical community and families about their options," she said. "The worst thing that could happen was that nothing would happen. And the complete opposite happened."

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