

# Stem cell treatments help Janesville boy

By GINA DUWE

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Photo 



Photo by [Dan Lassiter](#)

Brandon Meinke is held upright in an Easy Stand, a device that keeps him standing to strengthen his muscles for up to a half hour at a time at his Janesville home.

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Photo by [Dan Lassiter](#)

Brandon Meinke strengthens his legs with a stationary cycle. His grandmother Sharon Vaughan and sister Taylor Bonczyk look on.


**Photo** 



Photo by [Dan Lassiter](#)

Brandon Meinke stands tall and supports himself with his hands on his knees in the living room of his grandparent's home in Janesville. Brandon went to China in October for stem cell injections to improve his spinal muscular atrophy.

JANESVILLE — Gripping a small folding chair as he pushed himself up, 4-year-old Brandon Meinke flashed a smile.

Slightly hunched with his hands pushing on his thighs, Brandon stood with his feet flat on the floor, something he couldn't do just months ago.

“If I move, I fall down,” said the blue-eyed boy.

But standing on his own is improvement and success for Brandon, who has spinal muscular atrophy. Brandon continues to improve since an October visit to China, where he received four stem cell injections and intense physical therapy.

The Janesville Gazette first wrote about Brandon and his family in September, when they were raising money for the \$20,000 cost of treatment and travel. Seven weeks after their return, Brandon’s grandparents, who raise him in their Janesville home, said the trip was worth every penny.

“Absolutely,” said Sharon Vaughan, who went to China with Brandon and his other grandmother, Tina Pufahl.

## **Treatment**

The genetic disease affects Brandon’s motor neurons. He is missing the gene that produces a protein to protect his nerves, leaving his nerves to deteriorate and die, causing paralysis, said Ron Martin, Brandon’s grandfather.

Before the trip, the muscle tone in Brandon’s legs was gone, so he couldn’t support himself, Martin said. He crawled or rode in a wheelchair.

At Qingdao Cheng Yang Peoples Hospital in Qingdao, China, Brandon received a stem cell injection into his spine every four days with physical therapy in between. It’s a procedure unavailable in the United States.

“You’ll see instant results, but it really takes eight to 12 weeks to really get the impact,” Vaughan said.

Injected stem cells—the cells Brandon received were from umbilical cord blood—migrate to the problem and program themselves to do whatever the body is missing, Martin said.

After Brandon’s second injection, he was able to pull himself up along the bed and walk around it, Vaughan said.

“He hadn’t done that in over a year, two years probably,” she said.

The treatment cost \$20,000. The family raised enough money to cover the treatment and costs while in China, but they still are paying off more than \$4,000 in airline tickets.

Brandon became a star while sightseeing. Chinese people were infatuated with his blond hair, and teen girls wanted pictures with him.

“He got really used to a lot of attention,” Vaughan said.

## **Progress**

Just like any 4-year-old, Brandon makes up conversations between two of his superhero figures, he attends preschool and he looks forward to riding the new bicycle his grandpa had waiting when he got home from China.

“I’m going to do tricks,” he said of riding his bike.

Since returning from China, he can peddle a bike and do something he never could before—climb stairs. During therapy in Madison, Brandon pulled himself up, held on to railings with both hands and walked up a flight of stairs that were half the size of normal ones.

“He’s never, ever done that,” Vaughan said. “It shocked all of us because I’ve never seen him do it.”

Therapy is helping Brandon strengthen his leg muscles, knees, and ankles. If he tried to stand months ago, his heels would raise only an inch because of the atrophy of his muscles.

In China, Brandon got three hours of therapy a day, but the family’s insurance pays for only two half-hour sessions a week here. That’s leaving the family to do as much as they can on their own.

Martin plans to build some of his own therapy equipment, including a set of the 3-inch stairs.

Brandon stands daily in a device that stretches and strengthens his muscles, keeping his shoulders, hips and knees in a straight line, sometimes while doing electro stimulation, too.

### **A new family**

Since the first newspaper story, the couple has fielded media calls and contacts from other families in similar situations nationwide.

Martin and Vaughan trade stories about parents they've talked to and joke about the "Waltons in China," referring to the bonds they formed at the hospital with other families receiving the same treatment.

"I think they just wanted to know somebody that (went) over there and find out what happens. It's not a scam," she said.

When Brandon received his diagnoses, the family was told, "'This is what it is, this is what's going to happen, and basically that's your only option, and you have to deal with it,'" Martin said.

"I don't think either one of us were willing to accept that," he said.

Martin said it was unlike him to ask for financial help for the trip, but he knew it was beyond his means.

"If we're helping other families in the process," he said, "then I guess that's a way of paying it back."

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Nearly two years after her trip to China for stem cell injections, Brooke Barels continues to do well and maintain her improvements, her mother Vicki Barels said.

Brooke, 11, has glucose transporter deficiency (GLUT-1), a spontaneous gene mutation that leaves her with cerebral palsy-like symptoms and delayed brain development.

Brooke received six stem cell injections in March 2007 at Xiaoshan Hospital in Hangzhou, China. Before that, speech for Brooke was difficult and limited to strings of up to three words, and she could only walk with a walker.

Since the stem cell therapy, Brooke's motor skills increased, she's made cognitive improvements and she's walking with a cane.

Words spill out without modeling, Vicki said.

"I would say at this point, we're seeing somewhat of a plateau in her gain," she said. "But I feel pretty lucky."

"Looking back, I'm so glad we went," she said.

Brooke is one of only 120 children worldwide with GLUT-1.

She continues intense therapy in and out of school. She's also part of a study at Columbia University in New York City that's following the development of children with GLUT-1.

"They're really keeping a close follow on how they're responding to different interventions," Vicki said. "The goal is some kind of gene therapy success with them.

"She's showing us that we made the right decision," Vicki said.

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