

Family trying to raise money for child's surgery in China

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Blood from an umbilical cord is injected into the spine. In a matter of weeks, or even days, children who were born sightless report being able to see more light and make out shapes.

It sounds as if it could be the latest treatment offered at a top university hospital. And Katrina Stewart's efforts to procure the procedure for her visually impaired son are like those of thousands of parents who canvass the country in search of health care's latest offerings of hope. The difference is, this is China.

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To help the Stewart family, contribute to the Family Fund for Brandon P. Stewart, ENT Credit Union

Stewart, who lives in Ellicott, is trying to raise \$75,000 to take her 7-year-old boy halfway around the world for a stem cell procedure praised as a miracle cure by parents and patients but questioned by some scientists in the West who want more proof that it works.

The government of China has spent millions on the biotech industry and is extending its advancements to patients worldwide. One Chinese company benefiting from the investment, Beike Biotechnology, Co., offers the umbilical stem cell therapy to Americans at a time when regulation and politics have stymied such procedures in the U.S.

Umbilical stem cells are not from embryos, a subject of intense political debate.

Even so, these stem cell procedures have been criticized by some research purists who say the treatments lack the extensive clinical tests required of medical advancements here.

Beike and its advocates argue that Western bureaucracy is keeping life-changing care from patients who can't wait decades.

For Stewart, the question is simple: Can it help Brandon?

She is soliciting people for tens of thousands of dollars in hopes that her son — visually impaired since birth — can recognize faces and distinguish steps from cracks in the sidewalk.

They would be small victories his doctor here admits he'll likely never have with treatment that's available in the U.S.

Beike has treated eight children with Brandon's form of blindness, and all have reportedly gained increased sight.

Stewart doesn't expect 20/20 vision for her son. She just doesn't want to be left with the what-ifs. "I'm willing to accept any outcome, but if I don't try I will always wonder."

Health risks, so far, have been low. The two main risks, infection or a misplaced needle in the spinal canal, have never occurred, according to Beike.

Brandon's story

When he was 6 months old, Brandon Stewart was diagnosed with optic nerve hypoplasia, in which

the optic nerve fails to fully develop in utero. It's one of the most common causes of childhood blindness.

Brandon, a soft-spoken child with a penchant for cupcakes, does not live in total darkness. He can make out a few colors and foggy objects or people when they are just a few inches in front of him. Yet he fears cracks in the sidewalk because they appear to be steps, and trees because their branches hit when he gets too close.

In 2004, the Stewarts left Garden City, Kan., for the Pikes Peak region, where Brandon could attend The Colorado School for the Deaf and the Blind and have access to better health care.

Katrina quit her job as a Finney County sheriff's deputy. Her husband, John, quit his job as an assistant manager of a trucking company. He owns a dump truck and is self-employed. She helps him run his business.

The boy, who had fallen behind his schoolmates in Kansas, has flourished at the Colorado Springs school.

Even so, his parents struggle to come to terms with his blindness. Katrina Stewart said Brandon admires his dad and talks about wanting to drive some day. Such statements hurt. "It's hard for me to tell him that he can't because of his eyes," she said.

She said it's emotionally difficult to explain the world around Brandon that his 12-year-old sister, Courtney Harris, and 2-year-old brother, Nicholas Stewart, can see for themselves.

"Going up to the mountains, he sits there and looks bored or looks down," she said.

A story of hope

Late last year, Stewart saw a news report about a girl about Brandon's age who had the same condition. The girl had been treated by Beike, Stewart said, and her family reported that she could see in ways doctors here hadn't thought possible.

The story made Stewart cry. She turned to the Internet and found a world of similar claims from parents and patients: Children with severe visual impairments could recognize their parents and the world around them.

That led her to Kirshner Ross-Vaden, a suburban Chicago nurse who is Beike's vice president of the Foreign Patient Division and lead medical consultant.

The 7-year-old company began taking foreign patients in 2005. Since then, it has treated 2,500 people, Chinese and foreign, for a variety of ailments, including brain injuries and degenerative diseases.

Although Beike reports a 100 percent success rate for optic nerve hypoplasia, results for other medical problems have been mixed.

The Stewarts applied for treatment, and Brandon was found to meet the criteria. That, though, may have been the easy part.

The Stewarts concede that raising \$75,000 to pay for a little-known treatment thousands of miles away could be a tough sell.

Already, one organization, which she asked not be named, declined to help.

Other people have confused umbilical stem cells with embryonic stem cells, which have been hotly debated as a right-to-life issue.

The family's dump truck business has been sluggish this winter. And although other families pursuing the treatment have taken out a second mortgage or tapped their home equity, the Stewarts rent their home.

Persuasive stories

The family's pitch includes stories of children such as 2-year-old Cameron Petersen.

The boy was 3 months old when he was diagnosed with optic nerve hypoplasia and pituitary problems that left him blind and sickly, said his grandmother, Carol Petersen, of Port Charlotte, Fla. "He was at Children's Hospital more often than not," she said.

Today, she said, he plays like a healthy child and appears to see new objects. In her mind, there's 90 percent improvement.

She points to a time in church when Cameron began looking up at the bright lights. "Cameron started turning in circles watching these lights," she said.

On another occasion, the boy's brother took a toy out of a diaper bag. Cameron looked at his brother and took the toy back. "I know that there was no way on earth that Cameron possibly could have done that before," she said.

Adult patients, too, have returned from China with tales of newfound abilities from the same treatment.

Jim Savage, a Houston lawyer who became a quadriplegic after a diving accident, told The Associated Press in a recent story about the procedure that he was able to move his right arm again for the first time after his accident. He also reported greater abdominal strength and more sensation in his skin.

How it works

At Beike, which works with several Chinese hospitals, umbilical stem cells are injected into the spinal canal, where they essentially bathe the spinal cord and brain.

Because the cells have not yet become specialized, in theory they can repair damaged nerve cells and restart the development of healthy ones.

Dr. David Lee, Brandon's Colorado Springs ophthalmologist, called it an "interesting idea." Considering the lack of options available here and the seemingly low risks of the procedure, he said he was not opposed to the family's plans.

"I think that it's one of these things where it makes sense that it could potentially help," he said.

At the same time, he said, the Stewarts should temper their expectations. With the expense and travel, there's potential for disappointment if significant results don't come.

Beike, and China's biotech industry in general, have taken criticism from some Western doctors

who fear the treatment is being rushed to the marketplace without the scientific rigor of places like the United States. They say patients' testimonies could result from a placebo effect, in which — considering the cost and the journey — they simply believe there has been change. Petersen dismisses that idea.

“His favorite cartoon,” she says about Cameron, “instead of putting his ear toward the sound, now he'll look at the TV. He just sits there and stares at it.”

Ross-Vaden, the Beike representative who was in China and answered questions by e-mail, said the company has kept extensive documentation and is now translating its information from Chinese to English.

She said China has outpaced the U.S. in biotech science because the government has made it a priority and funneled millions into biotech.

It could be a decade or two before Beike's procedures come stateside, if at all, she said. Patent disputes, the politics over embryonic stem cells and a preoccupation with clinical trials are roadblocks to approval in the U.S., she and others said.

A middle ground

Dr. Peter A. Singer of Toronto's McLaughlin-Rotman Centre for Global Health was part of a team that conducted an in-depth study of China's biotech industry, including Beike. The study was published in January's edition of “Nature Biotechnology.”

He considers himself a Beike “agnostic.” As a physician, he believes patients' stories matter, while as a scientist he also believes people eventually deserve hard proof that something works. Beike, he said, needs to find a middle ground between anecdotes and proven data.

“There comes a point in time where families like the one in Colorado deserve a better answer than ‘Well, we think it works or we wouldn't be doing it, and you should just come and give it a try.’”

Katrina Stewart, though, needs no convincing. She talks of the children like Brandon who have been treated having a “brightness” about them when they look around.

She said she'll continue to learn Braille, help Brandon adapt to his dark world and come to terms with his disability. The difference, she said, is being able to say to herself she's tried everything.

At the same time, expectations are hard to hide. On a sunny afternoon at the school, where she and John have come to pick Brandon up for a doctor's appointment, she talks about the trip. When Brandon asks why they would go to China, she tells him his eyes are “broke” and need to be “fixed.”

The boy asks, “If they don't fix them what are we going to do?”
She cries.

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