

Stem cell treatment in China helps restore girl's sight

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Blue Springs, Mo. —

Doug Black found out his daughter Lydia was blind when she was just 3 months old. Doctors told him there was no cure and no hope that she would someday see.

"They were very adamant about it," said Black, wrestling coach and special education teacher at Missouri's Blue Springs South High School. "They told us, 'There is just nothing you can do.'"

Now at 6 years old, Lydia is part of an experimental stem cell treatment that has already begun to give her vision that she never had before.

Earlier this year, Lydia underwent stem cell treatment in Hangzhou, China, under the care of Beike Biotechnology.

The treatment uses stem cells from umbilical cord blood. During her five-week stay, Lydia received four spinal injections and one intravenous injection of umbilical cord stem cells.

Lydia's blindness is caused by a birth defect, septo-optic dysplasia. It's a rare birth defect characterized by the underdevelopment of the optic nerve, deficiency of one or more hormones of the pituitary gland and the absence of a midline part of the brain. In some cases, the disorder can also cause intellectual disability, though retardation did not present itself in Lydia. Doctors hope to develop the optic nerve, the nerve that transmits information from the retina to the brain.

Stem cell treatment for vision problems is not available in the United States.

Lydia's mother, Juli Olmstead, with whom Lydia lives in Columbia, found out about the treatment after getting a phone call from her mother. Her mother told her about a magazine article that she read about another girl with septo-optic dysplasia who had received treatment and had gained some ability to see.

Olmstead made some phone calls to other people who had already gone overseas for the treatment and did a lot of research before applying to get Lydia treated by the Chinese company.

Beike Biotechnology is funded by Beijing University, Hong Kong University of Science and Technology, Shenzhen City Hall and the China State National Fund. The company has been focused on stem cells since 1999 and has been treating patients with stem cell injections since 2001.

Kirshner Ross-Vaden, vice president of the Foreign Patient Division and lead medical consultant for Beike Biotech, said in an e-mail that 15 children and one adult have been treated for optic nerve disorders, with all showing some vision improvements. Beike also treats patients with many problems including cerebral palsy, brain damage and Parkinson's disease.

Some American physicians are wary of using stem cells to treat vision problems.

Dr. Ian MacDonald, an ophthalmologist and geneticist at the National Eye Institute, part of the National Institutes of Health, is skeptical of using stem cells to treat septo-optic dysplasia because of the complexity of the optic nerve. The optic nerve is made up of thousands of axons, which are tiny fibers that are used to transport information from the retina to the brain.

"Stem cells are ideally suited for cells undergoing constant renewal, such as bone marrow," MacDonald said. "If you transplant cells, what would enable those neurons to actually hook up in the right pathways and enable vision? What would guide the axons to line up in their proper locations?"

MacDonald said the experimental stem cell treatment is not available in the United States because there has been a lack of experimental work done to enable human experimentation. MacDonald says the overseas companies have bypassed the experimental phase and gone directly to humans.

"In the U.S., the basic scientific studies that would enable us to (use stem cells to treat humans) have not been done," MacDonald said. "The animal work has not been done to treat an animal model and then undergo human trials."

He said strict experimental protocol in place in the U.S. would block any human trials without animal testing having already taken place. Considering this, he said it will be a fairly long time until stem cell treatment will be done for vision problems in the U.S.

MacDonald said he would not recommend a patient undergo stem cell treatment because, without animal testing, the procedure is unproven.

Black, Olmstead and Lydia traveled to China on Jan. 8 to begin stem cell treatment and returned to Missouri on Feb. 7. About a week after Lydia's first treatment, Black noticed the first sign that she was beginning gain sight.

"We were at the hospital in China, and they had this Christmas tree," he said. "It had lights on it, and it was right behind the nurse's station. We were just walking and she stops and she points, what's that? She could see the actual Christmas lights blinking on and off.

"It was pretty amazing. My heart just kind of dropped. I got a little bit emotional."

Since returning from China, Lydia's vision has gradually improved. The doctors who treated Lydia said they expect her vision to improve for up to 18 months after treatment. Black said the treatment is already having a huge effect on her life, and he is glad that she was able to receive stem cell treatment in China.

"(Before the stem cell treatment) Sometimes she would get in a big hurry and she would run into a wall," Black said. "She'd say, 'I hate that wall. I hate that. It hurts.' You know that's sad. Now when you see her start to run around again, she stops and you can see that it's working. When it's hard on us, who knows how hard it is on her? I know I'd do anything for her, and I know her mom is the same way."

Before treatment, Lydia could not see anything. She only had a small amount of light perception. Lydia was so light-sensitive that she had to wear sunglasses everytime she went outside.

Since the treatment, Lydia recently has started to see silhouettes and can go outside without sunglasses. During a recent test involving two balls of different colors, she was able to tell that they were different colors, though she could not tell what colors they were.

Who is the first person Lydia wants to be able to see? Black said that when asked, Lydia would tell you, "Ryan Seacrest." No matter what time she goes to sleep on Friday night, Black says she will wake him up on Saturday morning at 6 a.m. to listen to "AT 40" hosted by Ryan Seacrest. She says, "Is my show on yet?"

Black said Lydia sees a doctor in Columbia, Mo., for follow-up appointments every few months. Soon, she will begin the next phase of treatment using a hyperbaric chamber. Black estimates that there is an 80 percent chance that she will have to go back to China for more stem cell treatments.

Lydia's vision improvements have come at a high financial cost. Since the stem cell procedure is experimental, none of the costs were covered by health insurance. Black said the price tag of the treatments and travel for the five-week trip to China ended up totaling around \$35,000.

The upcoming hyperbaric chamber procedure will cost \$5,000 every week.

Many people from the Blue Springs community and across the state have helped pay for the immense costs. Her parents created an organization called Lydia's Lights to gather funds and make people aware of Lydia's needs.

Black said Lydia's Lights has held several fundraisers in Blue Springs as well as in Columbia, such as poker nights and restaurant benefits. Lydia's Lights has also received a large sum of money through donations from the public as well as sponsorships.

"It's awesome," Black said. "Just when we got back, seeing the list of people that have been gracious enough to give; some people I don't even know. People are just willing to give and it's pretty incredible."

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