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Divide And Conquer

Long Island Families Turn To Controversial Stem Cell Research To Help Cure Their Children



Written by [Jaelyn Gallucci](#) on Aug 6th, 2009 and filed under [Featured](#), [News](#), [Our Children's Health](#), [Special Series](#). You can follow any responses to this entry through [RSS 2.0](#). You can leave a response or trackback to this entry



Every weekend, 8-year-old Brianna Bermudez of Bay Shore sits behind a bright yellow table with a bucket of lemonade and a red vase on the corner of West Leila and Manhattan Avenues in South Tampa with her grandmother. Her roadside profits, nearing \$4,000, would have sent most kids into early retirement from the lemonade business a long time ago. But Brianna has a much bigger goal in mind. At 50 cents per cup, she's raising money for her 1-year-old brother, Bryce, born legally blind, to undergo a \$50,000 procedure in China that could possibly, within weeks, let him see his sister's face for the first time.

Regenerative medicine is making progress, and the possibility of growing human organs, repairing spinal injuries, reversing birth defects, Parkinson's disease, Alzheimer's, autism, diabetes, and literally mending broken hearts, is moving rapidly from the realm of miracles and into the world of science. And with federal

funding for stem cell research now restored, never has the potential been so great or the hopes so high for the millions of people who, in some way or another, have been told, “I’m sorry, there is nothing we can do.”

New York State allotted \$600 million of state funds—the second largest state-funded program in the nation—to find ways to beat a long list of odds. It seems the only thing standing in the way now is time. But time is something not everyone has, or is willing to give.

THE CLOCK TICKS...

When the Food and Drug Administration (FDA) approved the first clinical stem cell trials in January on patients paralyzed by spinal cord injuries, the focus was on safety assessment, the first step of many in determining whether a treatment will work. The approval itself came after a review process that took more than a year. Altogether, the FDA estimates that it takes eight years to test a drug or treatment and bring it to market.

“The go-ahead to test products of embryonic stem cells in patients is an important first step,” says George Q. Daley, immediate past-president of the International Society for Stem Cell Research. “But only the first step on a very long journey.”

The chance to speed things up with overseas experimental procedures not yet approved in the U.S. has long been a draw for people with debilitating and fatal conditions.

BEATING THE ODDS ABROAD

Bryce was born with optic nerve hypoplasia (ONH), a condition that results in an underdeveloped optic nerve that cannot send visual signals to his brain. It is considered incurable. But 7,000 miles away in China, Beike Biotechnology claims to have the ability to restore eyesight to those with ONH.

“There are kids getting approvals within months [in China],” says Debbie Semis, Bryce’s grandmother. “Here? God only knows when this will ever come here.”

Since no research on these procedures has been published in established medical journals, and the side effects are unknown, the U.S. medical community in general is not receptive to these procedures abroad. But for those with no other options, it is worth the risk, especially after hearing the testimonies of those who claim to have had even small successes in other countries.

“If he can see, any eyesight at all, I’d be so happy with that,” says Semis, who will take her grandson on the month-long trip to China. “Without sight, people do manage, but if there’s some kind of hope somewhere, let’s try to see what we can do.”

Overseas clinics like Beike offer treatment for other disorders as well, including Spinal Muscular Atrophy (SMA), a rare, degenerative motor neuron disease that 5-month-old Sophia Gaynor was born with in February. But Sophia’s parents have no plans to leave the country. You see, when federal funding was restricted in 2001, stem cell research in the U.S. didn’t come to a complete halt. Privately-funded and state-financed studies were still underway.



RACE AGAINST TIME

Vincent and Catherine Gaynor of Wantagh are used to taking matters into their own hands. Because SMA is so rare, affecting only one in every 6,000 babies, doctors with decades of experience told them not to worry when, after two weeks, they noticed Sophia wasn't moving much.

"The doctors said she was absolutely fine—just a lazy baby—and there was nothing to worry about," says Vincent Gaynor.

But the Gaynors were persistent and after five weeks their pediatrician suggested they have Sophia tested for SMA. She tested positive.

"They told us to 'take her home and love her,'" says Gaynor, who says he and his wife were told they only had six months, at most, two years, with their daughter.

Sophia's body does not produce a particular protein which enables the body to produce or maintain muscles and she will gradually lose her ability to swallow and breathe on her own.

There is no cure for SMA, but the Gaynors hope that Sophia will be one of nine children accepted in a clinical trial at the Reeve-Irvine Research Center at the University of California, where she would undergo an experimental stem cell procedure. Clinical trials like these allow patients with terminal illnesses access to experimental treatments early on in the FDA approval process, before they are marketed.

"We need help in funding to get this trial going now," says Gaynor. "It is literally a race against the clock."

The Gaynors have already raised \$80,000 to help speed up the privately-funded study, but are trying to raise \$200,000. They are hoping the experimental treatment will start in January, before Sophia is too old to qualify for it.

The procedure will use an existing line of embryonic stem cells, created through in vitro fertilization. These cells are considered the gold standard in stem cell research because they are unspecialized, capable of renewing themselves in large quantities through cell division and "pluripotent," meaning one cell, the size of a decimal point, has the potential to turn into millions of cells which can then turn into any of the body's more than 200 tissue types.

"There is a lot of interest now whether you can take adult stem cells and induce them into more pluripotent cells," says Dr. Wadie Bahou, Professor of Medicine/Hematology and Vice Dean, Office of Scientific Affairs at Stony Brook University. "You're essentially programming them to be embryonic cells."

Adult stem cells, taken from fully developed organs and tissues, do not have the same ability to reproduce and are organ-specific. An adult liver stem cell cannot be made into a cardiac stem cell, for example, where an

embryonic cell can. But preliminary studies performed in mice show promise that this could possibly be done in humans one day—an important step in overcoming some of the opposition to stem cells by those against using human embryos.

“I have no problem with stem cell research,” says Lorraine Gariboldi, executive director of The Life Center of Long Island. “My objection is to the embryonic stem cell. That really is the only objection from the pro-life community.”

Another potential alternative to embryonic cells is cord blood, which contains blood-forming cells used for decades in transplants for patients with leukemia, lymphoma and other blood diseases.

“The advantage of cord blood is we already have experience with bone marrow transplants, but they are limited by the fact that they can only be used to treat blood diseases,” says Bahou. “Whether or not cord blood can be programmed is a logical question.”

Although U.S. studies cannot prove that cord blood can be used for treating anything other than blood diseases yet, doctors in countries like China and Thailand are claiming they can be. Bryce’s procedure will be done with cord blood stem cells.

Although embryonic stem cells are the best bet right now, scientists still face challenges like how to precisely control the transformation of human stem cells into the exact cells of different organs, how to keep the body from rejecting them, and how to make sure these cells stay where they are supposed to be and don’t cause cancers in other parts of the body.

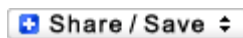
“I think that there is tremendous potential,” adds Bahou, who expects a lot of progress in stem cell treatment in the next two years. “We’re just not quite there yet.”

How long it will take to get there, and whether scientists in other countries have arrived there sooner, are questions that can’t be answered for sure. But for those waiting, whether or not a procedure in China will work or a clinical trial will come through in time isn’t a consideration.

“I don’t know what I’m going to do if it doesn’t happen,” says Vincent. “When you’re dealing with a child with a fatal disease, you do things you wouldn’t normally do. What is your other option?”

To make a donation to Sophia Gaynor or Bryce Mastrototaro, visit www.sophiascure.com or www.myspace.com/brycesight.

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