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## Risk vs. hope: South Floridians go overseas for stem cells

By Nancy McVicar  
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Kayce Barnes, of Margate, has taken her 7-year-old daughter Brianna to the Dominican Republic twice for infusions of stem cells she hopes will keep her alive -- an experimental technique not yet approved in the United States.

Brianna has Batten's disease, a rare, fatal degenerative neurological condition.

"If there's any chance to save my daughter's life," she said, "I'll do it."

Barnes said she made the trips because stem-cell treatments are unavailable or only in early stages in the United States.

Slowed by political opposition, embryonic stem cell research is limited to a small number of cell lines that qualify for federal research dollars. Private companies have raised more than \$440 million to advance their work outside the confines of federal funding, but for the most part are still in the early stages of laboratory work and animal experiments.

Several states have enacted stem cell research programs, but they are in their infancies. In Florida, the Supreme Court has been asked to sort out the language in competing proposals for constitutional amendments -- one that would prevent spending money on embryonic stem cell research, and another that would require the state to appropriate \$20 million annually for 10 years to pay for such research. Voters could decide the issue in 2008.

And it is expected Congress will take up the issue again next year.

Opponents of embryonic stem-cell research argue that the work is unethical because they say it requires ending a human life -- that of an embryo.

"We are in favor of all types of adult stem cell research and using umbilical cord blood," said Lynda Bell, spokeswoman for Florida Right to Life Committee. "We support any research that does not require the destruction of a human embryo, but when you're destroying human life to do experimentation, that is wrong."

As the debate rages, some desperate patients are going to other countries -- China, Mexico, the Dominican Republic, Brazil, Portugal, Sweden and elsewhere -- hoping for miracle cures now.

Brianna's treatment, offered by a California company called Medra, is performed at a hospital in the La Romana region of the Dominican Republic.

A stem cell trial to treat Batten's disease is planned at Oregon Health and Science University's children's hospital, but only six children will be treated initially and Brianna is not a candidate.

"She was denied from that trial because they want kids who are less medically involved, kids with very few symptoms," Barnes said.

Researchers in the United States have successfully treated conditions such as sickle cell disease, some genetic diseases, and immune deficiencies using umbilical cord stem cells, but the treatments require permission from the FDA and other regulatory oversight, such as institutional review boards, safeguards that may be lacking in other countries.

Bernard Siegel, executive director of the Genetics Policy Institute, which has offices in Wellington and Washington, D.C., and has organized several international meetings of stem cell researchers, said going offshore for such treatments is risky.



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"We pay close attention to these so-called stem cell therapies that are taking place outside the United States, and my own personal view is that we must take a very cautionary approach to this," he said.

Out-of-pocket costs can be high, \$20,000 to \$25,000 on average, and critics say there are few safeguards.

Siegel described a young quadriplegic from Texas who flew to Portugal for stem cell treatments.

"She had some cells implanted into her, and she did have some improvement, but she spent a lot of money and is still wheelchair bound," he said. "I think most physicians in the U.S. would say stem cell research has tremendous promise, but if you go to clinics overseas you're running a great risk."

David Aldrich, 49, paralyzed in a boating accident more than four years ago, thought there was no hope he would walk again.

But with his family's prodding and financial backing, the former licensed boat captain from Delray Beach traveled to China, where doctors are treating people with spinal cord injury and a variety of other conditions with stem cells obtained from umbilical cord blood.

Three scientific journals, *Science*, *Nature* and *The New England Journal of Medicine*, all have reported on China's stem-cell programs, and a British trade group that visited there two years ago reported that China might be at the forefront of international stem cell research.

"People are looking for hope, and it's too bad they have to go outside the U.S. to find it. That's all any of us have to look forward to is hope, to cure our disease or improve our quality of life," Aldrich said.

Aldrich's sister-in-law, Sally Aldrich, a retired nurse who lives in New Hampshire, found the site for Stem Cells China and began making inquiries, but the decision to go outside the country came after she also searched for help here.

"Back when David had his injury, I wanted to get him into the Miami Project [to Cure Paralysis, and the University of Miami School of Medicine] but they couldn't accommodate him," she said.

"There are people who are saying it's too early to do this, but David and Paul and I are adventurers. You don't get anywhere without risk," she said. "And for people like David and Christopher Reeve, all it takes for them to die is an infection."

Reeve, a prominent actor paralyzed when he was thrown from a horse, died Oct. 10, 2004, of an infection.

W. Dalton Dietrich, scientific director of the Miami Project, said he has had preliminary talks with the FDA about how best to conduct clinical trials using a combination therapy that the Miami researchers have shown can restore 70 percent of the movement in paralyzed limbs of rats.

"We're at that phase of the research where we're really thinking seriously about translating it into people, moving things from the bench to bedside, but it's difficult to tell how long that will take," Dietrich said.

When people consult him about going out of the country for stem cells, he said he advises against it. "We tell them this is premature and may be dangerous," he said. David Aldrich thinks the treatments and the physical therapy he received in China have given him more movement in his fingers and legs. His spinal injury is classified as "incomplete," meaning the cord was not severed. "I have more flexibility in my fingers. Now I can move both legs, I've got a lot more control of all my limbs. I believe what I'm experiencing now is a result of the strength training, and the rehab work while I was there. You can't just put in stem cells one day and get up and walk the next day," he said.

Aldrich said he hopes the climate for research in this country improves soon.

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