Child stem cell recipient heads home

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CHILD STEM CELL RECIPIENT HEADS HOME

By PAUL ELIAS, AP Biotechnology Writer Mon Dec 11, 7:57 PM ET

SAN FRANCISCO - Daniel Kerner's parents knew the experimental brain surgery was risky, but without it the 6-year-old surely would die. Last month in Portland, Ore., doctors for the first time transplanted stem cells from aborted fetuses into his head in a desperate bid to reverse, or at least slow, a rare genetic disorder called Batten disease. The so-far incurable condition normally results in blindness and paralysis before death.

Doctors don't know if the neural stem cells taken from fetuses — donated to a nonprofit medical foundation by women aborting early-stage pregnancies — will save Daniel's life. But the boy has sufficiently recovered from his 8-hour surgery to be expected to return to his Orange County, Calif., home Friday. The Jewish holiday of Hanukkah begins that night.

"We don't think that is a coincidence," said Marcus Kerner, who said a deep faith in Judaism and long hours of prayer prompted the family to volunteer Daniel for the risky procedure. Daniel was diagnosed two years ago and has since lost the ability to walk and talk. Daniel is the first volunteer of an experiment that plans to operate on five more afflicted children over the next year.

"He was a little boy who was basically waiting to die, now he's waiting to get better," said Kerner. He said Daniel recently called him "Dad" for the first time in two years.

The stem cells injected into Daniel's head aren't human embryonic stem cells, a research field for which

<u>President Bush</u> has limited federal funding because of moral objections. Nonetheless, the new cells in Daniel's brain do carry their own ethical baggage.

Anti-abortion groups oppose the research, which was banned from federal funding by President Reagan in 1988.

<u>President Clinton</u> removed the prohibition in 1993. "They are trying to give an aura that this is good when this is the most grisly of examples that can be given about abortion," said Gayle Atteberry, executive director of the Oregon Right to Life, the state's leading anti-abortion group. "They are taking the brains from babies."

Research opponents argue that beyond their moral opposition, there is the long list of failed fetal tissue transplant experiments — most notably those involving hundreds of Parkinson's patients over the last decade, none of whom have shown dramatic improvements.

But Martin McGlynn, chief executive of Stem Cells Inc., which developed and owns commercial rights to the experimental Batten treatment, said the current operation differs dramatically from previous fetal tissue transplant attempts. The Palo Altobased company is paying for the experimental operations. McGlynn said the injections Daniel received were "highly purified" stem cells selected for their ability to obey commands from the brain to replace damaged cells. McGlynn said previous transplants were crude by comparison because those researchers simply injected fetal brain tissue with little selectivity of needed cells.

Batten disease is caused when defective genes fail to make enzymes needed to dispose of waste made by brain cells. The waste piles up in the brain and kills healthy cells until the patient dies. Most victims die before they reach their teens.

The company's idea is to inject the sick kids with healthy, fetal neural stem cells that will "engraft" in the brain, which will direct the new cells to turn into cells able to produce the missing enzymes. The company's treatment showed promise in Batten-afflicted mice, but such an ethically charged test has never been tried before in children.

That's why Oregon Health Sciences University researchers have been trying to temper expectations since they first operated on Daniel on Nov. 14, steadfastly refusing to discuss the experiment except for a brief press conference two days after the operation."We don't want people thinking this is the best thing since sliced bread," said Dr. Robert Steiner, the lead Batten researcher in Portland.

The goals of the Portland experiment are modest and the results won't be known for at least a year. The researchers are mostly looking to see whether the stem cell injections harm Kerner and the other patients.

If they're satisfied that the side effects are mild enough, they will enroll more children in additional trials designed to measure whether the fetal stem cells are succeeding in loosening Batten's fatal grip. Batten afflicts roughly 3 out of every 100,000 children in the United States.

(SUBS 3rd graf to correct that Hanukkah begins Friday night, sted Friday day.)