

Stem Cell Therapy Experiences



~Parents Tell Their Stories~

By Anne Mancour

The subject of Stem Cell Therapy brings more questions than answers right now. Currently, there is only one research study approved in the U.S. to determine the viability of umbilical cord stem cell therapy on children with cerebral palsy. Dr. **Joanne Kurtzberg**, chief of Pediatrics/Blood and Marrow, is heading up this study at Duke University Medical School in North Carolina (see sidebar Q&A). With at least two Euro-Peds patients involved as subjects, we asked their parents about their experiences. Some names have been changed to protect the identities of patients.

“BRADLEY”

“Mariah” of Boston, MA, said her 3-year-old son, “**Bradley**,” was a perfect candidate for the Duke study. She and her husband had decided to save their son’s umbilical cord blood months before he was born. It was a decision they would later appreciate. At 2 years old her son was not walking yet and was diagnosed with a gross motor disorder. The idea that her son could participate in a groundbreaking stem cell trial for children with Cerebral Palsy first came to her early in 2008 while discussing stem cell injections with another parent at Euro-Peds who had taken her son to China for a stem cell injection procedure. “Too bad you don’t have your son’s cord blood saved,” the mom said in passing. “He could be part of that study they’re doing at Duke.” Mariah immediately began researching. She found out her son was also the perfect age to be considered for the study. After several months on a wait-list, she and her son traveled to Duke University Medical School in North Carolina in January 2009 for his first injection of his stem cells. After hours of evaluations, cognitive and motor skill testing he had his first infusion of stem cells through an IV in his foot. There were about seven people in the room, including Dr. Kurtzberg. Mariah was told that when a “smell of creamed corn” was evident in his breath, they would know that the stem cells were in his body. After the drip started, however, her son had an anaphylactic reaction (explained prior to the procedure as a potential effect of the chemicals that are used to store the stem cells). The infusion was temporarily stopped and Benadryl was prescribed. The doctor reassured Mariah that they would only proceed if it was a safe decision and fortunately they were able to continue. When they began running the drip of stem cells into his foot again, they delivered the infusion at half the normal speed. After 30-45 minutes, the drip was complete. Her son was observed for 3 - 4 hours afterward as a precaution and then an MRI was performed. The next morning before going back home to Boston, they met with a neurologist for more tests, and they signed an agreement saying they would come back a year later as part of the continuing research. “I noticed that his speech improved right away; that was encouraging.” There was also anecdotal feedback from his pre-school teachers about her son’s “incredible changes they never envisioned,” Mariah recalled. “My husband said it’s the best thing we’ve ever done.” In February, they should be getting the final results of their one-year follow-up visit with Dr. Kurtzberg from January ‘10. “If something starts to happen in six months, I would be very happy to see that,” Mariah commented. “I would do it again in a few years,” she concluded, although at this time, they do not have enough stem cells remaining for another full dose; the children in the Duke study are dosed on their weight, and her son only had enough for one injection. Even so, Mariah is encouraged that the research she is helping to do now will lead to a development for other children down the road.

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EMMA

The unorthodox decision to store their daughter **Emma**'s umbilical cord stem cells with Cord Blood Registry (CBR) turned out to be prescient for her parents, **Michael and Carrie Jabs** of California. Emma exhibited no signs of Cerebral Palsy until she was 8-months old when she had



Emma, daughter of Michael and Carrie Jabs, is a participant in a Duke University Study on Stem Cell therapy

a stroke, according to Carrie. When Emma was three, the Jabs' took their daughter and her stored stem cells to North Carolina after she was accepted as a participant in Dr. Kurtzberg's study in 2008. Emma was one of the first subjects. The experience was very similar to Mariah's son's experience but Emma's IV drip of stem cell solution was in her arm, and she had no adverse reaction to the solution.

"She's doing so much better than we imagined, but really, I don't know if it's the cord blood or not," Carrie reflected in a telephone interview, mentioning that Emma also does a variety of other therapies, such as constraint therapy in Alabama and Intensive Physical Therapy at Euro-Peds. The Jabs will go back to see Dr. Kurtzberg in June for their second follow-up visit, just one of many anticipated trips over the next decade to chart Emma's development. "I want to believe that it's helped her."

Links to news stories about Emma can be found at our Yahoo! group page (link found on www.europeds.org). Anne Mancour is the Marketing & Communications Coordinator for Doctors' Hospital of Michigan and Euro-Peds.

Q & A on Cord Blood Stem Cell Research

with Dr. Joanne Kurtzberg

Professor of Pediatrics and Pathology Director, Pediatric Blood and Marrow Transplant Program Director, Carolinas Cord Blood Bank

How many subjects do you need to complete the research on stem cell therapy, and how many subjects do you currently have in your study?

We have studied 150 subjects for a feasibility, safety study - now completed. We are planning a randomized, placebo-controlled study in 120 children to be opened in the next few months.

Is Duke's study the only approved trial, and who funds it?

To my knowledge, it's the only approved trial. It is funded by a Foundation, unrelated to CP or cord blood banking.

Why is the "smell of creamed corn" on the child's breath during stem cell injection an indicator that the stem cells are in the body? What causes this reaction in the body?

This is caused by excretion of DMSO, the cryoprotectant that is used to freeze the cells.

Are there any conclusive studies, in the U.S. or elsewhere, that proves stem cell therapy is effective in repairing brain damage in children with cerebral palsy?

No.

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