

## **Trommer Family Receives Cord Blood Donation from CordbancUSA**

By Emily Brown

Karen Trommer began emailing various cord bank companies when she was pregnant with her son Aiden. She wanted to find out if they were able to get a collection kit to her in time before she gave birth.

“I waited until the last minute and didn't think about it,” Trommer said. When Trommer was pregnant with her first child, daughter Kate, she had looked into the possibility of cordbanking but thought it was too expensive.

Cord banking is a collection system that saves the blood that remains in an infant's umbilical cord after birth. The umbilical cord and placenta used to be discarded without thought, but a discovery in the 1970s brought researchers to a discovery: umbilical cord blood could supply blood-forming stem cells that are found in a bone marrow donor, according to KidsHealth, an online organization devoted to providing doctor-approved health information.

Cord blood wasn't something that Trommer immediately thought of when deciding to have kids. “Of course, with Kate being my first, I thought I would have a healthy baby and never need it anyway,” Trommer said.

Kate, however, was diagnosed with neurofibromatosis, type 1, when she was 2 years old. The possibility of blood banking reentered the conversation in the Trommer household.

At the bottom of each sent e-mail, Trommer always puts a link to her NF donation page. “On my donation page I also have a link to my Myspace page and that page has lots of information about NF,” Trommer said. ([www.myspace.com/running4kate](http://www.myspace.com/running4kate))

The next day someone from CordbancUSA called Trommer on her cell phone. They told her they were trying to find someone that was pregnant and had requested information about cordbanking. “I told her she found the right person,” Trommer said.

CordbancUSA provides umbilical cord blood banking services and is based in California as service of BioBancUSA.

The representative from CordbancUSA found Trommer's phone number on the donation Web site. “She told me she was touched by our story and had talked to her boss,” Trommer said. CordbancUSA wanted to donate the initial fee for the cord blood banking. This donation was the first for CordbancUSA Trommer said.

The package was sent in time for the birth of baby Aiden with complete instructions.

“Our midwives were great about collecting the cord blood,” Trommer said. The midwives had done the procedure before and assured Trommer that the procedure would not be a problem. After the umbilical cord has been clamped and severed, the cord blood is saved in a sterile collection bag, according to

CordBancUSA. Cord blood can be used from both vaginal and a cesarean deliveries. The key is having the kit ordered before the delivery.

When Aiden was born, the midwives took the blood out of the umbilical cord. Eric, Trommer's husband, called the company to have someone come and pick up the blood, which is stored in an insulated container. The kit uses room-temperature gel packs to pad the container and provide extra protection. Once the cord blood arrives at the CordBancUSA lab, it is deposited into layers that separate the red blood cells and plasma from the white blood cells according to CordBancUSA. The blood is processed and preserved in a cryopreservation system that is computer-controlled.

"Cord blood does provide a type of stem cell that – although it is thought to have more limited potential than embryonic stem cells – is certainly very useful for stem cell research," Dr. Kim Hunter-Schaedle, chief scientific officer of the Children's Tumor Foundation said. "Also, it overcomes a lot of ethical concerns that some folks have about using embryonic derived tissue."

For Trommer, the possibility of cord blood brings optimism to a disorder that is filled with such uncertainty.

"It [cord blood] is so great," Trommer said. "It gives us another avenue of hope. If Kate has a symptom of NF that can be treated with stem cells, we might be able to use Aiden's cord blood."

Trommer admits however to being a little bit nervous. "I wasn't exactly sure how it would all work out, but everyone was great," Trommer said.

Kate does not quite understand what happened yet. She is only 5. But, Trommer believes that the years to come will provide understanding about a tiny gift with big possibilities.

Q & A with Dr. Kim Hunter-Schaedle

**What does this mean for NF developments?**

The thing about NF is that in most cases it is not a disorder that you are looking to replace tissue or regenerate tissue – quite the opposite for most folks who have large tumors they need removed. There are of course cases where stem cells might be useful for reconstructive surgery such as if we could figure out how to repair hearing related nerves after a vestibular tumor is removed or if another section of brain or spinal cord was affected and damaged after tumor removal. But these areas will benefit in the long run from general non-NF specific research on reconstructing the nervous system and in a sense these areas don't yet need NF specific research. Other potential areas for NF stem cells might be if you needed a bone marrow transplant/reconstruction but again these are areas that could benefit from non-NF related research in this area. That said, we can't see the future and there may be a major research development that would call for cord blood cells. Where

NF has a link today with stem cells is in basic biology research and trying to understand where tumors and other manifestations come from and the genetics/signaling role. For example, recently a particular type of cell that develops at a certain point in embryonic development in the nerve called a non-myelinating Schwann cell has been linked with being the causal cell for plexiform neurofibromas. So stem cells might be useful tools for researchers to study.

**Are there any dangers or challenges to think about?**

There is no danger or challenge in storing cord blood other than the ongoing cost of storage. Overall I would say that if someone has a gift or can afford to bank cord blood there is nothing wrong with doing that, and we can't know today what it might be useful for in the future...there is no application for them today that would necessarily immediately benefit the patient. So doing this is kind of taking out an insurance policy that may never be redeemable – but I know many folks do this anyway and it's definitely a personal issue.