

Mr. John and Mrs. Cathy Rizza
New England Cord Blood Bank, Inc.
153 Needham Street
Building One
Newton, MA 02464

Dear Mr. and Mrs. Rizza,

Thank you for helping to save my daughter's life.

In April, 1998, I gave birth to my first child, my daughter Cameron. Cameron was born with intestinal malrotation and duodenal atresia, which was found during an ultrasound shortly before her birth. Her intestinal defects were going to be corrected surgically at 2 days old. I was ready for that. What I wasn't ready for was the hand and thumb anomalies that weren't found on that ultrasound – problems that meant there was a much bigger – one that a surgery could not fix.

Geneticists were called in and many syndromes were discussed. I had an amniocentesis performed so all of the genetic problems tested for at that time were ruled out immediately. The physicians seemed baffled but one of the genetic counselors wanted to test for a "very rare and deadly" recessive genetic disease – Fanconi Anemia. During Cameron's surgery, the surgeon removed some extra skin to send to New York for testing for FA. When my daughter was 10 days old, I was told by a hematologist that she would live "about 10 years, and then die during a bone marrow transplant". I was told not to have any more children. She then left the room and I sat there with my head spinning, hysterically crying, wondering what on Earth to do.

I grew up with a stepdad who is a scientist and cancer researcher. We went to Woods Hole, MA every summer so that he could do research and I was surrounded by brilliant minds constantly. I knew about cord blood and stem cell research and the promises for cures that stem cells hold. Even though it was 1998 and stem cell research seemed like science fiction to most, I had read about so many things that looked so amazing with respect to what could be available in the future. I immediately called my sister in Boston, who was due in 4 weeks, and asked her if she would please bank her daughter's cord blood in case there was any chance of her being a match for my daughter since Cameron's cord blood would not help her underlying condition in the future. She agreed and has my niece's cord blood banked with you.

I have had 2 sons since Cameron's birth – both healthy and unaffected by FA - and stored their cord blood with you. Reese was born in May, 1999 and Conlan in May, 2002. I had a CVS performed with each pregnancy to see if they had FA, and had them HLA typed at the same time. Knowing where their cord blood is – actually being able to *visualize* the building gave me great comfort. Being in Boston, a place I lived for many years and home to one of the world's best medical communities, was such a "plus" when deciding what facility to use.

Fast forward to 2007. Cameron was being followed closely by hematologists. CBC after CBC, bone marrow biopsies and check-ups constantly. Her CBC levels, particularly her ANC, had dropped to the cut-off. St. Jude said it was time. We went to Minnesota to see Dr. John Wagner and Dr. Margie MacMillan to see what they said. It was time for transplant - time to call you and retrieve Conlan's cord blood. He is a 6/6 match for his sister and, thanks to you, I had his cord blood banked.

Cameron went through her transplant with very little problems. Of course we had the usual glucose issues from steroids and some nausea from chemo (but she did not actually vomit – ever), but she was eating the entire time and really amazed everyone with how well she was doing. The cell count in Conlan’s cord blood was very low so it took awhile for her counts to come in. But they came in and, when they did, they grew like crazy. We were home in Memphis on Day +61.

I can never express thoroughly in words how it felt to watch that bright red cord blood flow from the bag through my daughter’s central line in to her body. It was a re-birth. Conlan has always been my “sugar kid” who eats his dinner with great speed solely to be able to have dessert: 30 minutes in to the transfusion Cameron asked me for a Hershey’s candy bar – the first time in her life she had ever asked for chocolate. As I ran around the hospital looking at vending machines trying to find that candy bar (which I did eventually find), I *knew* the transplant would be a success. I kept thinking about the day of her diagnosis, my phone calls with NECBB, being able to picture where the cord blood was, all of the wonderful people I had spoken to at NECBB, stem cell research – you name it, it ran through my mind. I wanted to be able to hug someone from NECBB and tell them thank you for helping to save Cameron’s life. And maybe ask them for a Hershey’s candy bar.

As this year draws to a close I look at my daughter, who has never been healthier in her life, and feel such gratitude for you and what you do. Cameron is in 6th grade, gets all As and Bs, loves Miley Cyrus, make-up, all things pink, anything to do with Twilight and arguing with her brothers. Including the one whose stem cells saved her life. And I thank God for you and her physicians and all of the brilliant minds researching stem cells. And, of course, for my beautiful children; one of which would not be here right now if it weren’t for you.

Thank you. It seems like such a trivial thing to say for what you’ve done, but I don’t know what else to say.

Have a wonderful Holiday season and Happy New Year. You are, and will always be, a huge part of my life – Cameron is living, breathing testimony to that. Her picture is below – see what I mean about the pink???

All of my best to all of you and your families,

Leighsa McCommon
Mom of Cameron Perlish

**Cameron Perlish
Fanconi Anemia
Successful stem cell transplant using her brother Conlan's cord blood 9/7/07 at
the University of Minnesota**



THANK YOU NECBB!