



It was November 2010. Xavier was 8 years old as a 2nd grader. He wasn't feeling that well, complaining of a headache and feeling nauseous. Two of his teachers met me in the office when I picked him up to express their concern about Xavier's sudden health change. His skin color was yellow and his energy level was extremely low compared to all the other kids. I immediately called the doctor's office and as my luck would have it, the doctor himself answered the phone as their office was already closed for the day. He sent us to the nearest hospital to get some blood drawn to check for anemia. It was only an hour later that the doctor called us back; the phone call that changed our lives forever. Apparently, the small hospital lab could not even process his blood labs because his blood counts were so abnormal. They immediately sent the blood sample to Iowa City's hospital, anticipating the results to show Leukemia. Within another half hour the Hematologist called to tell me that we needed to get to the hospital as quickly as possible. The doctor, sounding very concerned, explained to me that we had a very, very sick little boy that needed immediate attention. Here we were, bombarded with this shocking news that our little boy had cancer...a cancer I knew nothing about! I was in shock and disbelief... I mean, he didn't act that sick aside from having a headache and being tired.

Once we got to the hospital at 11 pm, the nurses sprang into action...it turned out that his white count...the blood that fights off infection was 602,000. A Normal count is around 7-10,000. A typical high risk Leukemia patient has a white count of 50,000. Xavier's was 12 times higher than that! Some doctors there had never seen a count that high! He also had to have immediate blood transfusions of red blood cells and platelets. He was at severe risk of a stroke or heart attack and I didn't even know he was that sick! Xavier walked into the hospital that night when the nurses were expecting to see him being wheeled in. Within three days of being admitted, Xavier already had surgery to insert his port to ready him for his chemo treatments. We stayed at the hospital for ten days as they tried to make a treatment plan. Due to the extreme high white count, they were uncertain as the path so they just attempted the typical

treatment of a high risk patient. It didn't take long to realize that Xavier was going to be an atypical case. The doctors had many meetings with other oncologists around the world to get some insight into how to treat him. He had uncommon side effects to many of the meds and often left the doctors scratching their heads in bewilderment. He had weekly chemo treatments at the hospital and took about 6 meds at home twice a day. Each day, we prayed that the treatments would work. We just took him in and he got his treatment...there were no indications that the chemo was working until we did the monthly spinal tap. The first one is a forever disturbing image that I'll never forget. Xavier was screaming out of fear and the meds they gave him to calm down only made him scream more. They attempted to insert a very long needle into his spine to test for cancer cells. What should have been a quick procedure was difficult because his spinal fluid was so impacted with cancer cells it barely had room for the needle inside. 94% of his fluid was made up of cancer cells, which prevented the growth of the required healthy blood cells.

The doctors were hoping that after a month of chemo treatment, the cancer would be gone like in typical cases. Xavier proved to us again that his case wasn't typical. Weekly chemo treatments continued as did the countless meds at home...and finally three months later, at the end of March we received the news we had so impatiently been waiting for. REMISSION!

However, his journey was far from over. The doctors then decided that since it took him so long to reach remission and due to his high white count upon diagnosis that the only option he had to reduce the chance of a relapse was a bone marrow transplant. I had heard about the transplant procedure and it was terrifying! The most typical side effect were mouth and gi tract sores that were so painful you had to be on a liquid diet for at least a month until they healed. Another side effect was the risk of organ failure as your body refuses to accept the new bone marrow and therefore attacking itself as if the marrow were a virus or something needing to be destroyed. That side effect, called "Graft versus Host disease" came in four different stages of severity! Needless to say, I was terrified but knew that this was our only option of saving our little boy if he survived the procedure itself. None of our immediate family were matches to Xavier's marrow so we had to rely on an anonymous unrelated donor. Luckily within only a couple of weeks they found a match that was almost as perfect as if he were related to him.

We moved in to the transplant unit in June 2011 where he had more chemo and a week of total body radiation to kill all his blood cells in his body. At that point he was ready to receive his new bone marrow. It resembled a simple bag of blood that was infused into his body through his IV. Such a simple procedure for such a complex and terrifying method to save our child's life! Then each day afterwards, we held our breath and sat on the edge of our seats watching for those unpleasant signs of attack. Each day that progressed the doctors came in scratching their heads and smiling saying, they had never seen a patient go through this process

as easily as Xavier did. Not one time did he even get a mouth sore to cause him to not want to eat! He actually had me make frequent trips to Carlos O' Kellys for cheese enchiladas! One of the nurses said he had never seen that in the 25 years of his nursing career. So, although we were expecting to have to stay there a couple months, only 3 weeks post-transplant, we were released! Because of his lack of side effects and quick release, Xavier had the nickname of the "Miracle Transplant boy!"

It took Xavier a year for his body to start making his own immune system again, so the only time we left the house was our weekly trips to the hospital for infusions. His body was so weak it couldn't even fight off a temp on its own so anything over 100 meant he had to go spend a week in the hospital on antibiotics. A lot of those visits were on isolation which meant he couldn't leave the room. Two years of this second grader lying on the couch, too weak and tired and nauseas to do much of anything but watch tv, while his friends were playing outside and getting on the school bus right outside our house every day. It was a constant reminder of what cancer does to its victims.

We spent so many days wondering, hoping, praying, fearing, anticipating some good news that the chemo would work. That is the hardest part aside from watching your little boy go through this and not being able to do anything to help him. When he asks you with those inquisitive tears in his eyes...."was I bad, mommy, did I do something wrong to deserve this?" Believe me, this was a question I asked myself on a daily basis!

But, if you ask Xavier about his cancer journey, he will tell you that while the meds and chemo made him feel terrible, his hospital stays were actually not scary, but fun! Fun, because of wonderful people like the Dance Marathon volunteers and child life specialists. They would bring him activities, crafts, board games, and video games to play...this is what helped him through this. Things that most people would consider trivial and piddly things, but it's those things that he remembers, not the scary needle pokes and procedures and yucky meds. It's those days that as a parent you wondered how on earth you would be strong enough to be brave for your child, and then a Dance Marathon student pops in with a gift card for a free meal and free entertainment for my little patient! A simple free meal meant you could escape the walls of isolation and act like a normal person, eating a typical restaurant meal!

Those moments that we were allowed some feelings of normalcy meant the world to us as parents. It took our feelings of helplessness and puts them in the hands of the volunteers making our child smile and laugh during those scary unpredictable times! I remember feeling so overwhelmed with emotional stress that the thought of coming up with the energy to entertain your sick child or help him with his daily tasks at the hospital was a challenge. Knowing you can call on a volunteer to give you a breather or walk with you around the block

allowed you to clear your head and breathe some much needed fresh air! I actually was the first parent to benefit from and participate in the weekly DM walks! They were a true blessing!

This year, at the big DM event Xavier will be walking across the stage to celebrate his six years of being cancer free! That yearly event and the other family events throughout the year, means the world to us as a cancer family. To be able to mingle with families that shared the same feelings and experiences as us is beyond amazing! It reminds us of the wonderful support that Dance Marathon offers us! Another great piece of happiness is that we have had the pleasure of talking via email to his bone marrow donor who lives in Berlin, Germany! His donor was just 19 when he chose to save a life by registering to be a donor. He said it was the best choice of his life. One day I hope we will be able to actually meet in person.

The Roach family