

We tried for months to find out what was wrong with our son. When he was born he was a healthy amazing beautiful baby boy, our second son. We couldn't have been happier, and then it began. At first we thought it was colic, and then as he continued to not "grow out of it" we knew there was something else wrong. As the months passed our life began to turn upside down. Our son's weight dropped, he stopped meeting milestones and he continued to regress and deteriorate to the point where he looked like he did not even want to go on anymore. We fought so hard for answers. We stressed and searched and finally 10 months later, after numerous tests and procedures an MRI finally gave us our answer.

"Your son has a tumor in his spinal cord" ..... I am winded, yet calm....almost like I am outside of my body. I feel numb, like someone could punch me and I wouldn't feel a thing. I sit on the cot in our hospital room and stare, trying to focus on what the team of doctors is saying to me, trying to hear every word, though I am only managing to pick up the major words like tumor, spinal cord, and surgery.

"The tumor is very large; it starts at the top of the spine and goes approximately halfway down his back. We will be operating in 10 days and you need to get him to gain as much weight as possible before then. I know this is a lot to take in; do you have any questions right now? "

"Okay" are the only words that escape my mouth. I scan the room, looking at a sea of white coats and dress suits. I am holding our son tightly in my arms patting his back, I freeze, "Am I hurting him?" I ask completely horrified that I may be causing him pain. "Is he in a lot of pain?" "How big is the tumor?" "Is it cancer?" It all comes spilling out like vomit. I try to concentrate and listen as I receive answers to my questions. I look at my husband who looks lost and broken.

Everyone leaves the room; they leave us alone to digest this life altering news. We both sit there and stare straight ahead, we stare at each other, we stare at our son and then we cry. I feel like someone has just swung a baseball bat and hit me square in the head. My ears are ringing and I have one of the worst migraines ever. I feel very alone. My marriage has been unraveling from the previous months of stress; I am 27 and pregnant with our third child, who is due to arrive in less than a month from this exact day. The next ten minutes are full of crying and a few short sentences. We phone our parents, tell them the news and cry with them. Then we stop. Oddly enough I feel relief. We finally have an answer and they are going to fix our son.

I do not allow myself to get depressed, I refuse to get sad or allow myself to visit the dark place I know is lurking so close, I am scared to even think about it. I do not do any research on the internet, I want to know as little as possible, I want to cling to the hope I have and remain positive. I am scared if I do any research I will open up the door to that dark path and become very depressed.

The next ten days somehow fly by yet still feel like an eternity. I feel numb; I cling to my faith and the hope that we are doing the best thing for our child. We don't talk about the surgery, we enjoy every minute we have together.

November 2 we are admitted back on the unit. Tomorrow morning is the big day. My nerves are starting to rattle and I am feeling more anxious as I listen to the clock on the wall tick away. I don't sleep at all, I sit in a rocking chair holding our son as tight as I can, listening to each breathe go in and out. I just stare

at him and pray. I make deals with God; I make deals with myself.....trying to stay sane. At 7am, all too soon they come for us. I hold him the entire way to the operating room. It is so cold and sterile but I keep my composure. They sedate our son and I give him a kiss goodbye, I look back one last time at his tiny fragile body, hardly believing this is happening. As I walk back out to meet my husband I finally let myself break down. I sob uncontrollably; I want to race back in there and rip him off of the table I had just laid him on. I want to hold him tight and never let him go, I want to wake up from this horrible nightmare.

The minutes in each hour feel like an eternity. We receive word halfway through the surgery that everything is going wonderful, as well as can be expected. I continue to pray. We are finally able to see our son in PICU 9 hours later. We are warned what to expect, tubes, machines, equipment. I am not shocked by any of it, I am just so thankful I can finally see him again. The first few nights are awful, we have trouble controlling the pain, and I am completely helpless as I watch my son shake in pain as tears roll down his face, yet no sound comes out. The worst part as a mother is not being able to pick him up and hold him. I feel completely helpless and beat down. As the days go on he continues to get better and we are able to move up to the unit.

He is limp from the waist down, but moving his arms fairly well. The days start to run into each other, my hope starts to regain momentum and I start to feel some relief. I am so naive, thinking that the toughest part is long behind us.

Three weeks later we are finally home. Our son has the mentality of a one year old yet is reverted back to a new born baby, unable to even lift his head on his own. I go into labor and to add to the chaos we welcome a little girl. Life is crazy, most days I don't know whether I am coming or going. My family helps us so much. Life is so busy, appointments are the new normal, rehab is just part of our daily routine, and we spend a lot of time in the car. After nine months of grueling rehabilitation our son is walking pushing a walker. It is truly amazing.

As time progresses, call it mothers intuition, call it whatever you like, deep down I get a sinking feeling, I know the tumor is back. I know that we are not in the clear like we had hoped. I feel sick. I insist we do an early MRI, not wait the usual three months...I know we need to get this done now. Unfortunately I am right. The MRI shows the tumor is growing back and we learn that at the age of eighteen months our son is going to have to go through the same surgery again that he went through nine months earlier. I am completely devastated. It feels way worse than it did the first time. We now have been through this once and know what to expect and have to do prepare to do it all over again. Take all of the hard work our son has done and make him start all over again. I am scared, sad, but mostly I am so angry. I am so angry that my son has to endure this situation not once, but two times. I allow myself to be angry, I allow myself to cry, but never in front of the kids. Then I ask myself, what good is it doing to cry, how am I helping my child, my family or myself by crying? Other than to blow off a little steam by myself, crying is not going to get us anywhere, it will only move us backwards. It's a slippery slope of emotions we are walking on and it doesn't take much to get knocked down.....but it's how fast you pick yourself up, and how you face the obstacle head on and keep going.

So we face our obstacle head on. We muster up the courage, regain composure and go to battle. The surgery is another very long surgery, and just as hard on everyone as the previous one. There are more complications during the surgery than the first time, and we have more to deal with after the fact.

He develops two new lifelong conditions, which certainly affect him. I am relieved the surgery is behind us and we can move forward to the next step, rehabilitation. Our son will walk again, I am very confident of this. We are told that because of all of the complications during the surgery, he is no longer a candidate and if the tumors come back our only option is radiation.

Two months later my heart is ripped out of my chest. I know without a doubt that the tumors are growing back. It is confirmed in our clinic visit and I am hit by an imaginary train at full speed. I don't know how I manage to drive home, I don't remember much of the drive, but the minute I walk through the door I take one look at my husband and I break down. I can't help doing it in front of our three children, it just comes spilling over like a flood that has had a shaky dam and has finally been broken. I feel like someone has punched me in the stomach. I am emotionally beat up, unsure of how much more I can take, of how much more our son and the rest of our family can take.

This is our last hope we are told. If this does not work, we are out of options. Twenty-eight high dose radiation treatments start on November 4<sup>th</sup>. Our son is so sick we are hospitalized for four weeks. In everything he has been through I have never seen him as sick as he was now. My heart shatters into a million pieces. I feel completely helpless. I feel guilt, how could I, as a mother, be letting my child endure something so horrible? I know in my heart this is truly going to be the answer to our prayers, I thank God every night for healing our son, because I feel it down to my soul and I know it to be true with every fiber of my being.

Our son has been cancer free since, two years and two months later! It is amazing to know, truly know in your heart, that cancer is no longer plaguing your child. There have been many complications with infections and minor surgeries, having to have a finger amputated because of infection. There have been many hospitalizations since the radiation treatments, which have definitely affected the rehabilitation process.

Our son is still not walking unassisted, but has come so far with all that he has thrown his way. He is starting to stand for longer periods of time unassisted and is walking and moving his legs with assistance. It's amazing to see how far he has come, how far our entire family has come.

I try to maintain my positive outlook as we continue on this journey, a different journey than where we first began. The road of rehabilitation, a very long winding road, one that twists and turns and is very hard to see too far ahead.