

I remember the overwhelming joy when we found out we were expecting our second child in February 2008. Our 3 year old son had asked many times if he could have a baby brother or sister, and now our family would finally be complete. Needless to say, the news was great! Several weeks later, though, I had an emergency and went to my doctor to check on the baby. That day carried a mix of emotions as we learned I was having what they call, "One fetal demise & One surviving birth."

Miscarriage alone is heart rending, but knowing our other baby was doing well and hearing his heartbeat brought a sigh of relief. I felt confused, though, unsure how to wrap my head around our situation. The doctors labeled me as a high-risk pregnancy and watched my progress closely. They scheduled a C-section and a D&C to take care of the demise that my body couldn't. The night before the big day my emotions ran wild. I was excited to meet, see and hold our brand new baby, but I was also frightened. I was nervous about the surgery, and I had a terrible feeling something was wrong. My intuitions wouldn't budge. Though I tried, I couldn't sleep. My mind raced.



The morning of October 15, 2008 arrived. Little did I know, the course of our life was going to change in many ways. I was excited, but still nervous. We arrived at the hospital and everything started so fast. Nurses buzzed in and out, getting me ready for surgery. I kissed my son and family as they rolled me back to the cold operating room. I could hear all the noises of surgery and the doctor ask if I was ok. I kept waiting for our baby's cry. The doctors chatted with us trying to make best of the situation. I heard the doctor declare "It's a boy!", and as if to announce it himself, our newborn son cried! The nurses said, "Here mama here's your baby" and then whisked him away. He couldn't stay with me because, I had to endure another surgery.

After my second surgery, they took me to my room. I wanted my baby, to see him, to hold him. I needed him, but he never came. The nurse brought me a picture of him, my Max, informing me that he was having trouble breathing. She said they would bring him to me once he stabilized. Hours passed. The pediatrician came to explain that Max had begun having seizures, and they needed to transfer him to the NICU at Children's Hospital of Colorado, over 100 miles away.

The news shattered my heart. Tears flowed. I still hadn't held him. What if something happened to him, and I'd never hold my beautiful baby? My mind considered the worst, and all I could do was pray. God, please don't take my baby. I knew His will would be done, but to understand and cope in that moment wasn't easy to do. I needed my son. I needed to hold him and to love him.

My nurse pushed my bed into the nursery so I could be with Max. She placed him on my chest. He was perfect. Ten fingers. Ten toes. A cute little nose and the chubbiest cheeks. He was beautiful. As I held him, he stabilized. I spent what little time with him holding him and praying, asking God to heal him. But before I knew it the EMT's arrived, taking my little boy away to be prepped for the transfer. They brought my baby to me once more, but I couldn't say goodbye. I touched him, tucked his blanket around him, and I knew I would be with him again.



I asked when I could leave to be with my baby. They said at least three days. Hearing that my newborn son would be without his mother for three whole days wrecked my heart, and I became determined to get out as soon as possible. I needed my son, and he needed me. By God's grace alone, they discharged me the next evening. As my parents drove me the 100 miles, I anticipate seeing my baby again. We had spent so little time together.

We arrive at Children's Hospital, and they wheeled me up to Max's room in the NICU, right up to his little bed. Nothing can prepare you for the sight of your baby in the NICU. Seeing him covered in tubes and wires broke my heart. My baby was on oxygen. He had a G tube down his nose and into his belly. IVs and vital leads covered him. His closed eyes made him seem so peaceful. I dropped my head into my hands and sobbed. As my family comforted me I thanked God for our beautiful blessing.



As time passed the doctors prepared us for taking home a special needs baby. They told us he would need all this at home. They taught us how to take care of him. I felt broken. I didn't understand. He seemed so perfect, yet he needed so much help to survive. They performed EEGs, MRIs, blood tests, spinal taps, genetic/metabolic tests, but nothing explained the seizures.

The doctors put Max into a medically induced coma for six days. By day six of his life, I snapped out of my emotional roller coaster. We felt certain all his medications kept him so lifeless. He had hypotonia (no tone). He had no gag reflex. He demonstrated no response to pain. His eyes remained closed, and he couldn't eat or breathe on his own. As they began cutting back his meds, we noticed him waking up a little more.



Seeing him open his eyes or move a limb felt amazing. We felt like our baby was coming back. To hear those first sounds again brought tears of joy. At two weeks old he began to nipple feed. Everyday in the NICU, holding my precious baby, I knew no matter what happened, God had

blessed us with him. Weather he came home with special needs or not, he was our beautiful blessing.

Every time he reached a milestone we celebrated! The day he no longer needed the oxygen was a miracle - he could eat and breathe on his own. These “little” things many take for granted become major when your baby can't do them on their own. We watched Max accomplish all this while still not knowing when or if we would ever take him home. So many questions remained unanswered. Doctors couldn't tell us what had happened, what had caused his condition. At the time they couldn't diagnose Max with anything. The neonatal pediatrician labeled Max a “phenomenon”, and when he was discharged, he came home with only his anti-seizure medication.



We continued to take him to and from Denver for tests. With each test, we learned more about our little blessing. He had a heart defect, which we monitor yearly, and he has gene missing off a chromosome. Yet neither of these explained his seizures. Eventually, he was finally diagnosed with a seizure syndrome, we also learned what we had known in our hearts - Max also had Autism. We felt glad to finally have answers, but mixed with a wave of sadness.

This has been a seven year battle, but we've never given up. Max has been on synthetic pharmaceutical medications his entire life. These medications are supposed to control his seizures. They have caused more havoc than help. He's been on some that make his behavior erratic. Some meds make him so sleepy he's sedated like. He's had a bowel obstruction/blockage in his colon from severe side effects. His body doesn't produce sweat properly as a side effect, so I have to make sure he stays hydrated and that his body temperature is controlled. All these side effects and Max still had uncontrollable seizures.



He could have multiple seizures a day for several days in a row. His seizures affect his autonomic nervous system. When he has a seizure he turns blue, because his respiratory and cardiovascular systems are affected. He vomits and becomes incognite, because his stomach and urinary tract/bowels are affected. He's taken handfuls of medication twice a day his entire life.

Although, it's difficult to make him take these medications because I know they're toxic to his body, I have to. His doctors are all in Colorado, given his history they were interested in trying CBD. However, we live in the beautiful state of Wyoming where the choice to treat my son naturally is illegal.

I can choose to walk the outside of the grocery store aisles and purchase fresh organic produce and meats because that is what I feel is most healthy for my family, but I can not choose a natural alternative to heal my son. I have watched my son suffer at the hands of medical physicians and pharmaceutical medications that have not helped him.



Max is 7yrs old. He has his blood drawn often to check his liver enzymes and kidney function. He has gone through more in his 7yrs, than most grown adults have. I believe medical marijuana would give my son the quality of life he deserves.

Until you watch your own child lay lifeless and there is absolutely nothing you can do but pray, maybe you'll understand. The most difficult battle my head and heart play, is knowing medical marijuana is Max's cure and he can't have it.

I will never stop fighting. I also wouldn't change him for the world, but I will try to change the world for him. Max deserves it.



Sincerely,

A mother trying to change the quality of life for her son