

Amazing Macie

A mother never forgets the day her children were born. Those days are memories etched into a mother's soul never to be forgotten. Our family received a gift of love from above. A baby girl that was chosen to be a part of our family always and forever.



On February 15, 2007, Macie Kate Majeres was born. Her first breath on earth was at 5:14 a.m. She weighed 6 pounds 9 oz. She was absolutely gorgeous. A true blessing to John, Katie, Alyssa, Isabelle and Tommy.



Our doctor handed Macie to me, Katie. I remember the concerned look on his face. He noticed that she was missing skin on her forefinger and had some blisters on the top of her bottom. At this time, we didn't think it was a major concern as she was perfect in all other areas. She had beautiful skin otherwise and strong vitals. She was a perfect ten in our eyes.

The doctors had consulted with other pediatricians and thought it would be best if Macie was reevaluated at Mayo Clinic in Rochester, MN. So after a long evening of

labor and some hectic first hours of life, Macie and I rode in an ambulance to Rochester. John, Isabelle, and Tommy followed us there. Upon arrival at 11pm we got settled into a room in the PICU. We were welcomed with several doctors, interns, and nurses. This is when reality hit for us. We knew there was something that was "not normal". The doctors had made a preliminary diagnosis and told us it was Epidermolysis Bullosa or for short, EB. They strongly encouraged us to stay away from researching on the internet due to the fact that there were a lot of misconceptions about EB. The disease at this point was not well known and fairly new to research. They did refer us to an organization named, DEBRA. We soon discovered this organization and the people involved were heaven sent. There was a nurse that was very accessible with knowledge that was imperative to Macie's health. If she didn't know the answer she would connect us to other families that were able to help us understand this condition.

The following days were intense. We were trained on how to care for Macie. She started to develop a lot more blisters all over her body. The doctors had warned us of this because any type of friction or rubbing of the skin would cause the skin to blister. The diaper area was really sensitive and our biggest challenge.



Overall we were pleased with our care at Mayo. We had some great nurses. There wasn't much more Mayo could do for us, so they sent us home for a couple of days. We stayed with my parents for the weekend before heading home. We wanted to make sure we were comfortable with our new lifestyle. It wasn't until two weeks later, the diagnosis was confirmed that Macie had EB Simplex. EB Simplex is typically a type of EB that allows for a longer life. It doesn't usually cause scarring. Most EB Simplex babies will lead a life with some limitations. The older the EB Simplex baby is the better he/she seems to get. We were relieved to hear this news. We were ready to take on the challenges for our Macie.

Pictured below was Holly, our nurse. We loved her!



We were anxious to get home. Macie was ready to meet some of her family. She had many grandparents, aunts, uncles, friends that loved her so much!



Our daily routine consisted of our home health care nurse coming in the morning to bath and bandage Macie's wounds. Macie struggled with gaining weight. Her body was 85% wounds so a lot of her nutrition and energy went to healing.

Macie was a fighter. She would often sleep through her bandaging time. We truly believe that God was there for her at this time to hold and comfort her. She would rarely cry during this process.

Macie fought for several months. In our spare time, John and I would research and talk to other families to see how we could make her more comfortable. This was extremely helpful, but it also caused some confusion for us. Our stories weren't really comparing to other families with babies of EB Simplex. This was so

perplexing to us that we reached out to DebRA several times. We scheduled a visit to have Leslie come to our house on July 16, 2007. She is a representative that travels the world to meet families like ours with babies like Macie. Leslie had a baby girl with EB, Junctional Herlitz. She taught us how to better bandage Macie and brought new products to us that helped with wound care and the diaper area. We soon became great acquaintances. She was extremely knowledgeable. We had many long talks and discussions. She showed us pictures of her baby, Lauren. This was a bittersweet moment. Leslie was so gracious, but when we saw the pictures of her baby, John and I knew that Macie was misdiagnosed. It was on this day we knew in our hearts that Macie had Junctional Herlitz EB, the fatal kind of EB. We NEVER gave up hope for our butterfly baby. We knew that we needed to seek more help from expert doctors in Cincinnati to get the answers we needed. We made this our goal.

During Macie's 5th month of life we spent many days in the hospital. She was having difficulty breathing because of internal blockage. Her wounds were getting deeper, causing more pain. She had difficulty drinking from her bottle and often would aspirate.

Our local doctor was more than agreeable. Whatever we desired, he was sure to get us what we needed for her. We wanted to get to Cincinnati Children's Hospital. Soon after we were on a medical flight to Cincinnati. When we got there, the doctors were still perplexed. They wanted us to intervene with a trachea so Macie could breathe without struggle. This was a difficult decision due the fact that with EB you can have many complications with skin irritations and blistering internally and externally. John and I decided that we would do what the doctors were asking, but with some hesitation. The evening before surgery, we prayed to God that we were doing what was best for our baby girl. If it wasn't what He wished, we prayed for that sign to know His answer. The morning of surgery we awoke by a doctor coming in to tell us that Macie's blood levels were abnormal. This told us that she was bleeding internally. God gave us the sign we were looking for. We cancelled the surgery. We took our AMAZING MACIE home. She was ready to be with our heavenly Father.

It was a very rough day as you can imagine. We find so much comfort knowing we did what Macie and God wanted us to do. Macie had a peace about her that day.

She smiled every minute, I swear. She was telling her Mommy and Daddy it was OK. Her fight was over.

A smile we will cherish forever! Macie is telling us, I will love you always and forever!



Our family has many happy memories of Macie. As her mother, I remember all the times I snuggled with her. She was by my side her whole life. I will never forget how she would wrap her fingers around my finger. I nursed her until she could no longer because of blistering in her mouth. Her smile could light up the room. I am honored to be called her mommy.



John, her daddy, remembers her scrunched up nose when she smiles, her soft, silky mittens, and her beautiful blue eyes. I always enjoyed taking her for a bike ride.



Alyssa loved her smile. Macie loved her big sister, Alyssa.



Isabelle, her sister, would comfort her by stroking her eyebrows and sing to her, Twinkle, Twinkle Little Star. She was by her side always.



Tommy would tickle her tummy and he was the first to discover her first tooth. He would hold her on the couch and watch Sesame Street.



Macie passed away on August 15, 2007. She was exactly 6 months.

“The purpose of life is to have a life of purpose”

We continue to keep Macie's legacy alive by hosting Maciefest annually. Maciefest is a celebration of life. We have raised over \$25,000.00 for DEBRA in honor of our Amazing Macie.



Every year on February 15 for Macie's birthday we will do something as a family. She will always be with us spiritually until we meet for eternal life. What a magical day that will be!