Incompatible with Life, Fatal abnormalities, Failure to Thrive, Medically Fragile, Stubborn, Tough, Intelligent, Funny, Loving, and Happy are all words I have heard to describe this 6 year old boy.

In May 2010, we heard those first few words that I just mentioned at a routine 20 week ultrasound. Up until that point, my pregnancy of our second child was completely uneventful. Our older son, Braiden, was almost 2 years old and we were excited to expand our family. The ultrasound technician stared at the screen with a concerned look on her face, kindly excused herself for a quick moment to speak to a doctor and left my husband Elliott and I staring at a dark ultrasound monitor unable to see any anatomy of our unborn child. We were quickly brought into a room to meet with my doctor who delivered the terrible news to us. Something was in fact terribly wrong with our unborn baby and she had scheduled us for an appointment with the high risk maternal fetal medicine or MFM doctor. 3 days later our trip to the MFM doctor was the worst day of our lives. I had another ultrasound, they looked at things in more detail and we sat across the desk from the specialist where we heard the words that the abnormalities of our unborn baby appeared to be fatal. That the abnormalities were incompatible with life. The lack of amniotic fluid around the baby was most likely going to result in the lungs not being properly developed. The fluid that they saw in the kidneys indicated that they most likely would not function. And the fluid in the abdomen would probably keep rising, compress on the heart, eventually stop the baby's heart and I would end up delivering a still born baby. Those words heard by any parent would take your breath away instantly. Our hearts were shattered into a million tiny pieces and we didn't know how we would ever recover. We were given our options: we could terminate the pregnancy or carry on and prepare for the worst. We kept thinking that this had to be a horrible dream. We left office with a plan to visit my regular ob weekly to check for the baby's heart beat and we were forced to prepare for the day when we would be told that our baby had passed away in utero. During the next few weeks we visited with our church. We discussed the situation with our priest and planned a funeral. We went to a funeral home and picked out a tiny casket and we visited a cemetery where we found a cemetery plot that we would lay our baby to rest once he was born. Things were very scary and heartbreaking for us.

Early in September when I was about 36 weeks pregnant, my amniotic fluid levels started diminishing again and the drs. decided that it was time schedule a c-section. The Drs. were unsure what would happen upon delivery and we were terrified. On September 3, 2010 at 8:12 AM, everyone in the operating room watched a baby boy being born, crying a loud cry and bringing tears to many eyes in the room. I lay on the operating table in complete shock. After he was born, he was whisked away to the neonatal intensive care unit or NICU and tests were began. After a few hours I was finally able to see Ethan. There in the tiny isolette, lay our little baby boy. A true miracle. He had tubes and wires coming out of every part of his body. He was on a cpap machine to give his lungs some additional support. His abdomen was filled with fluid. But he was alive. And breathing. And that was more than we had ever expected to see. Within the first 24 hours, the tests that the NICU team ran confirmed a diagnosis of Prune Belly

Syndrome or PBS. PBS is an extremely rare syndrome that causes a group of birth defects including bladder and urinary tract issues, and poor development of the abdominal muscles which causes the skin to wrinkle, like a prune. The cause of PBS is unknown and there is no cure. It occurs in about 1 out of every 40,000 births and 95% of the cases are male. Once we learned of the syndrome, it followed with learning the statistics of the effects of PBS. 20% of babies with PBS die before birth, 30% die from kidney problems within the first two years of life, and the remaining 50% have varying degrees of urinary problems their entire lives. Those statistics were very frightening. Surprisingly, 3.5 weeks later, after he learned how to drink from a bottle, maintain his body temperature, not have any breathing issues while eating, and the doctors knew his kidney function was stable, he was discharged from the NICU weighing 5 pounds.

Of course, with all of this we had a lot of care when we arrived home and several doctors to visit. We were finally able to introduce Braiden to his baby brother, as he was too young to visit him in the NICU. Our homecoming didn't last long and 3 weeks later, when Ethan was just 6 weeks old he was admitted to the Pediatric Intensive Care Unit, or PICU, of the hospital for pneumonia. That was the first sign of just how medically fragile Ethan was. He had been completely fine just 24 hours before that. We remained in the hospital for about 2 weeks due to the infection requiring IV antibiotics. The pneumonia took a toll on Ethan's underdeveloped lungs and he was required to come home on continuous oxygen and 5 different medications to help heal his strained heart and lungs.

After that first pneumonia hospitalization in October, Ethan would enter Mercy Children's hospital at least monthly through March for urinary tract infections and feeding issues.

In March 2011, our world almost stopped again. Ethan began breathing heavier than normal at home and we took him to the pediatrician to have them listen to his lungs. The dr. decided to have him admitted to Mercy Children's and called over to the hospital to let them know we were coming again. Since he was born we had not spent more than 3 weeks straight at home without a hospital admission. The PICU team began working on him as soon as we arrived and within the first 24 hours it was determined that he had contracted RSV. RSV to most babies is similar to a chest cold. It's a virus so you can't treat it with antibiotics. You can only help manage the symptoms. Ethan had been receiving monthly injections at home to help protect him from RSV but that wasn't enough. The doctors all poured in, hour after hour, day after day, to tell us how bad this virus could get. The respiratory therapists worked hard on him giving him breathing treatments, turning up his oxygen, putting him on a higher flow oxygen, and moving him to a bipap machine for a last ditch effort of non-invasive breathing support. We sat as spectators to this horror story because there was absolutely nothing we could do to help our son. His body had to fight this virus off on his own. Early one morning, after about 5 days into this admission, Ethan hit rock bottom. The oxygen level in his blood measured down into the 40% range, which indicated that he was in respiratory failure. The room became crowded with doctors, respiratory therapists, and nurses who all began working to help him. The therapists

bagged him and cranked the oxygen level up as high as it would go, but that still didn't work. We stood there watching this little 8 pound baby gasp for air and saw his chest pump up and down so fast just trying to catch his breath. The team told us that they would have to put Ethan on the ventilator because his lungs were so sick and his body was just too tired to fight anymore. There was no guarantee that the breathing tube would help but we were out of options. Once the breathing tube was inserted and Ethan was all hooked up to the ventilator, we were allowed to be back in his room. We walked in to see our small lifeless baby laying in his bed. When babies and young kids are put on the ventilator, they are sedated to keep them from moving and dislodging the tube. And there he was. After about 10 long days, his lungs seemed to improve enough that they team felt like they could take him off of the vent and move him to the bipap machine. Ethan had required extremely high doses of sedation drugs as a result of being on the vent for so long and once those drugs left his system, he immediately started withdrawing. We watched him shake uncontrollably, flail his arms and legs, twitch and move around while his body underwent symptoms similar to what a drug addict would experience without those medications. This lasted for about a week and it was very hard to watch. Again, we were completely helpless and had to rely on his body to be strong enough to adjust without having those medications in his system and simultaneously heal his lungs. Ever so slowly, things started turning the corner. We remained in the hospital for 6 straight weeks. We learned all of the new things that we would need to do to manage his care at home and we joked saying that we became instant nurses having to do all of those things but the truth is, it just became natural to do because we were living with a chronically ill child. We were finally discharged after 44 long days.

For the remainder of his first year, Ethan was hospitalized 2 more times at Mercy Children's. Once for another UTI and the other was another pneumonia admission. During that pneumonia admission he was also placed on the ventilator and once his lungs had healed slightly he had two surgeries performed. The first surgery was performed on his urinary tract to help alleviate the recurring UTI's and another to put in a more permanent feeding tube into his stomach called a g-tube. Once that g-tube was placed he no longer had to have the tube running through his nose which was a welcome change.

After his first birthday, he started having less and less hospital stays. He had surgery when he was 2, to correct bi-lateral hip dysplasia and he wore a full body cast from his chest down to his ankles for 12 full weeks.

In November of 2015, we travelled to Dallas, Texas and Ethan underwent a muscle transposition surgery performed by a doctor that has specifically perfected this procedure in children with PBS. During the surgery, muscles from each quad in his leg were partially detached and run up into the abdomen to allow for him to have some stomach muscles and his abdomen area was tightened up. In addition, a urologist performed a surgery to correct some issues with is urinary tract. The muscle transposition surgery was a huge deal for him. With the addition of some stomach muscles, his balance and posture improved, the chronic constipation

issues that he suffered from got better, and his respiratory function seemed to get stronger. He now has a little more strength to cough when he gets sick, and the winter of 2016 was the first cold and flu season since he had been born that he was not hospitalized for any respiratory illnesses.

Just last month, Ethan had his most recent surgery which was on his spine to begin correcting his scoliosis that happened as a result of PBS. The surgery placed 2 implants and a metal rod into is back to help guide the future growth of his spine over the next several years. Every 3 months, the dr. will adjust the rod magnetically. He will need 2 more surgeries over his lifetime on his spine to completely and permanently correct this scoliosis.

Since birth, Ethan has also been in physical, feeding, and occupational therapy. He attends weekly therapy appointments through Mercy Ped's Therapy and during his school day. He started doing HIPPO therapy about 2 years ago, which is therapy that is done by horseback. Studies have shown that HIPPO therapy has tremendously helped kids with their strength and muscle control, but also in other ways like helping deal with anxiety, focus, speech and language, and expression. He has benefited immensely in many areas from his weekly HIPPO therapy sessions.

Ethan's weekly feeding therapy appointments have helped aid in his lack of interest in food which started as an infant. He developed a severe oral aversion from being on oxygen for a year and a half and having been on the ventilator for extended periods of time. He has never eaten a full meal by mouth and is still fed 4 times a day through his g-tube with a high calorie formula. At 6 years old he only weighs 30 pounds. Each week he works with his therapist to simply take a bite of food, chew it and move it from one side of his mouth to the other and eventually swallow it. It seems so basic but as a baby he never developed those muscles in his tongue. He now has found quite a few foods that he is interested in eating but he still has lot of work to do in this area.

On top of all of the medical conditions, hospital admissions and therapy appointments, Ethan is followed regularly by 8 pediatric specialists. He has spent more time in the waiting rooms at appointments, had more blood draws, ivs, scans, x-rays, and procedures done in his short 6 years than many of us will have in our entire lives. He does all of this without ever complaining. He is intelligent and tough and has an extremely positive attitude about everything that he has to do. He is stubborn. Which is one of his biggest strengths and has allowed him to endure all that he has had to deal with since he was born. He is strong willed and has no problem bossing around any doctor or nurse that cares for him. He tells them what he wants them to do first and they listen and do what he says. He is such a loving kid. He admires both his older brother Braiden and also his younger brother Cameron. We see Braiden watch over him and be so protective of him and Cameron looks up to him and wants to do exactly what Ethan does.

On countless occasions we have heard people say that they don't know how we have handled everything that has gone on with Ethan. And to be honest a lot of it has been rough. We see

kids similar in age to Ethan be able to do things that he struggles with, like running, jumping, and playing sports. We have to worry each time we hear him cough that he might be hospitalized. We worry that someday his kidneys may decide that they don't want to work as well and he will need dialysis or even a kidney transplant. It is unfair that our family has been separated so many times due to hospital stays. That every year since he was born Ethan has had spent time in the hospital for an illness or surgery. It stinks that Ethan's closet is completely filled with various medical supplies that have one time or another been used to support him in hopes of keeping him healthy. But if you walk through the halls of Mercy Children's Hospital or through the outpatient pediatric offices you will see children and parents in the same boat as us. It is hard to see kids so sick, hooked up to all sorts of things to help save their lives or to see children work so hard to do things that many of us find so simple, like walking or talking. It is painful to think that some kids are so sick inside those walls of the hospital that their parents may not get to bring them home. But what has helped us get through all of the struggles Ethan has had, is that we are privileged to have a front row seat in witnessing a miracle. Ethan has taught us how to be resilient and brave. He has taught us to not sweat the small stuff. He has taught us how to appreciate the ordinary moments of day to day life a little more than we may have done without him. And we know that God has big plans for him. Maya Angelou once said, if you are always trying to be normal you will never know how amazing you can be. This quote seems quite fitting when describing Ethan's life. He is far from being normal but he is truly amazing.