

Charlie



July 1st, 2007, my mother's birthday and also the day that changed our lives forever. We were celebrating my mother's birthday and also planning my wedding the following year. While driving home, re-playing conversations during the barbeque, I made a stop at CVS for a pregnancy test. The longest two minutes of my life, it was confirmed when I saw those two lines. I didn't know how to tell my husband (fiancé at the time), so I just tossed the box to him. He and our daughter were ecstatic. You see, we as a family had prior conversations that my daughter (6 years old) needed a playmate. I think he looked at the box and its contents and then called his whole family and my mother to give her another birthday wish – that she was going to be a grandmother again.

I went to the doctor who stated because of my age (26), that he was making the pregnancy “high risk” with a due date of February 2nd. I was as happy as can be but I kept wondering why my age had anything to do with making the pregnancy high risk. I was young and healthy. Maybe the doctor was just being pessimistic, but because of my status, I had to undergo several blood tests, visit the genetic counselors and make frequent visits for ultrasounds. My quad screen test results came back positive for down syndrome, spinal bifida and cerebral palsy. However, the doctor needed another test to be certain. For days my fiancé and I would walk around wondering why this was happening to us. You pray for a healthy baby but never expect news like this so early in a pregnancy. It turned out that I was 14 weeks along, not 17 weeks as the doctor expected, so the doctor asked if I would like to have the quad test again. I declined; I didn't want to go through another scare. My due date was changed to February 28th, two days after my daughter's birthday.



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Week 16, my fiancé was unable to come to the ultrasound, so my sister came with me to find out the sex of the baby. Everything seemed routine with the technician. I kept asking questions; “What is that, is it a boy, what it that, is it a girl?” Her answers were very vague. I noticed she was concentration on one area. Without a medical degree even I can tell she was looking at the heart. I looked at my sister who has a medical background, lip syncing to her what is going on. Even she was puzzled by the events. The technician excused herself. Before she could leave I asked if everything was okay. Her response was, “I have to get the doctor.” I broke down and cried in my sister’s arms. Today was supposed to be a great day to find out if I was having a daughter or son, our newest addition, and I can’t even get a simple answer. The doctor came in the room and said for me to settle down. Everything would be okay, she just needed more photos. She asked if I had any concerns or questions. With all my might I tried to compose myself. I asked, if it was a boy or girl, but I knew something was wrong. Again I asked, “What’s the matter with the heart?” The doctor said, “Well it’s a boy.” She wasn’t clear exactly on the diagnosis of the heart but she also could not get a clear view of the heart because of his angle. She handed me a list of hospitals to choose from, saying I would need a fetal echo. My sister and I left the doctor’s office in tears. I am going to be a mother again, I thought, I’m going to have a boy, a son. My daughter is going to be a big sister, and my fiancé is going to be a father again. With these happy thoughts, how can I be happy if there is something wrong with my baby’s heart? Even if the doctors are certain, there’s still that possibility. While in the car, I looked at the list of hospitals and chose Children’s Hospital of Philadelphia. I made the earliest appointment possible, which was for October 23rd, for the fetal echo in their heart program.

I can still remember that visit as if it was yesterday. We walked in the room with the technician who stated that we were not to ask questions as she needed to concentrate on the ultrasound. It was the longest 45 minutes of our lives, looking at the heart of our baby beating, red and blue blood spots on the screen indicating the blood flow. Finally the technician said she needed to check with the doctors and make sure she has enough photos. I looked at Chuck and couldn't help but have a bad feeling and started to cry. When the door opened, the technician said she needed more photos. Before I could lie back down on the table, I had to break the silence and asked, "Is everything alright?" She answered, "Nobody told you that everything's not alright?" I looked at Chuck and cried some more. How could this be happening? After the fetal echo they led us to this room no bigger than 4 x 4. The cardiologist and heart program specialist came in the room and the first I heard was, "Your baby has hypoplastic right heart syndrome, coarction of the aorta, tricuspid artesia and transportation of the great arteries." I tried my best to compose myself and try and understand what they were trying to explain to me. As others before, we were given three options: Compassionate Care, Abortion or the 3 stage Norwood Procedure. I don't remember much of the conversation. During the ride home it was very quiet; I couldn't remember that conversation either.

Halloween was very hard for us, seeing all the babies dressed up in their Halloween outfits, so healthy and sweet. The recent doctor's visits just hit us so hard, we couldn't sleep, we couldn't eat, we weren't talking. It was Halloween night that we decided we were going to stay with my mother. If anyone was able to help us decide what to do, it was her.

Through symbolic spiritual intervention we decided Charlie was meant to be in our lives. He had a mission and his mission was



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to live. We were married that November and began to be joyful about this pregnancy. For once we were able to be happy for the arrival of our son. We did however decide that I would stay home with the baby until his third surgery. I had my baby shower and was so excited to see all the boy clothes, blue things and have everything come together. My due date came and went, so the doctors decided to induce me March 2nd, at 8 a.m. The whole family and I woke up and made the trip to the hospital. During the car ride, I had all these questions with no answers; if I would need a C-Section or a natural born as I planned, how much was he going to weigh, how soon would he have to be transported to Children's Hospital, how much time would I get to be with him and would I be able to hold him? We arrived at the University of Pennsylvania, ready for the arrival of my son, just to have the doctors say they had unexpected unscheduled deliveries all morning. We again had two options: have the baby in the emergency room or stay around the city and wait for them to call me when a room was available. We decided to stay in the city and make a family trip to the Franklin Institute. Throughout the day I noticed a striking pain in my back and in my stomach. Every time I tried to sit, the family would switch exhibits and my mom would encourage me to continue to walk some more. Instead of elevators, we took the stairs, instead of walking through an exhibit, we would walk around an exhibit. Again I noticed the pain was getting stronger. Seven years prior, we had a family portrait taken in front of the heart exhibit, so there was now irony and meaning to having our picture taken again. We went to dinner, only to have the hospital call; there was a room available. We made the second trip to the hospital for the doctors to tell me what I already knew. I was in active labor. Knowing full well what the baby was going to go through, I wanted to have a natural labor. Doctors came in the room, indicating that I may have to have the

baby in the operating room. They said that only one extra person would be allowed, since CHOP staff would have to also be in the room to prep Charlie. Because of his condition, he was going to be a small baby. My husband chose my mother to be in the room with me. Although the labor was tough, the pain was tougher. However, at 3:28 a.m. Charlie was born, weighing 7 pounds 15 ounces. The doctors were wrong, he was a big boy. As soon as he was born, they led him into the next room and I only had a quick glimpse of him. I could hear the healthy cries for me. They brought me back to my room where we showed my husband and sister the picture of our new boy. The hospital staff, to my surprise brought Charlie into my room. I wasn't able to hold him but we were grateful to have him baptized in the hospital. The whole time his eyes never left my site as if he already knew who his mommy was. I sincerely thought I was going to be okay with Charlie being transported next door, but it was heartbreaking to see him go. I tried to contain myself but sadness took over. Once Charlie was settled at CHOP, my husband and sister went over, as my mother stayed with me. That morning I was able to finally visit Charlie. Seeing him hooked up to all those monitors and IVs was very hard; you never want to see your child in that state. He opened his eyes a couple of times. I let him know that Mommy was with him and he went back to sleep peacefully.

That morning was also the first time that brother and sister met each other. His surgery was set for the following day with Dr. Spray, the most renowned doctor of the East Coast for this surgery. The following day, my husband, mother and I were able to hold Charlie for the first time. I took a picture of him, knowing that his body would never look the same, a kiss for my baby boy and prayed to God to look after my boy. We had a brief conference with Dr. Spray, then we were led into the family room, awaiting



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details by our nurse during the surgery. Finally, we were led in the room with Dr. Spray, where he told us the surgery was a success. We would be able to see him momentarily. I was discharged from my hospital but I never left Charlie's bedside. We saw Charlie with his incision (his zipper) and hoped he wasn't in pain. I promised to never leave his side and kissed his forehead. Mommy was here. Days were long but nights were longer. But we were grateful to have nightly visits from family. It's beautiful to see that this little guy was loved by so many. Through the echo and X-ray it was determined that Charlie has "hypoplastic right heart syndrome" and "double inlet left ventricle". Charlie was having difficulty holding food down and had blood in his stool, so they delayed feeding him until he had 24 hours of no problems. Finally but slowly, one by one, the lines were removed. Day 10 in the hospital, Charlie was able to have a room of his own and by day 12, Charlie was finally discharged.

Our daily lives entail giving him Lasix twice a day as well as aspirin. We have bi-weekly doctor visits, monthly echograms and EKGs. When Charlie left the hospital, his oxygen saturation level was in the high 90's but as the months progressed, his level is slowly dropping. In his most recent cardiologist appointment, his oxygen saturation level reached 71. At his next visit, the doctors will schedule his Stage 2 procedure. I try to keep myself occupied, taking endless photos of everyday events, trying to both mentally and physically prepare for the inevitable. It's strange that it's only been 4 months, but it feels like a lifetime ago that Charlie was in the hospital. We will have to relive it once more in the next upcoming weeks. Looking back at the last year, it makes it all worthwhile looking into his blue eyes, for this little guy has left his imprint in all of our hearts and lives.

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