

. . . a difficult decision after diagnosis of conjoined twins . . .

Our Twins

I am married to a NYC firefighter. We have been together since 1992, we bought a house in Westchester in 1997, and kept putting off the idea of "kids" for two more years... every time it came up we talked, and decided two more years. Well, we were not careful at all and after a total of 9 years I started to worry if we would ever conceive. One magical night we did and now we have a wonderful 5-year-old boy. Well, we started to gently try again because I was so afraid to go through another terrible c-section. Also, I thought the clock is ticking, I am 36 years old and I was told by several friends who have fertility issues to hurry because fertility "drops like a rock" after 35. Well, we did it. On July 9th, my husband's birthday, we found out that I was pregnant - what a birthday gift. I was so excited and wanted to tell everyone. My husband is much more cautious and private about these things so he advised me to wait a little to tell everyone.

I was showing almost immediately and the news started trickling out. I am a high-risk patient and was under the care of a perinatologist. I saw the heartbeat of our "singleton" at 6 weeks. I started to spot on and off and with my low progesterone level I was so afraid we would lose this "one" baby. Around 8 weeks I went to a BBQ on Long Island. I felt like a strange little pop and got the sinking feeling that we would lose the baby. In that instant from happily buzzing around the party I was reduced to the slow hunched walk. I indeed started to bleed pretty heavily. We stayed overnight at my mother-in-law's house and I prayed so hard that night to not lose the baby. I went again to my old perinatologist for a second opinion about the low progesterone level and to witness the lovely heartbeat again. This pregnancy was indeed much different than the first. When I was pregnant with my son I would get really nauseated or tired and would return to my bright eyed and bushy-tailed self quickly. I felt a general lousiness with this pregnancy but

complained more about being out of breath with palpitations and I was easily irritable. My second opinion saw the "singleton" and prescribed a progesterone supplement, I took that one night, my heart "flip-flopped" and it was like I had a bunch of caffeine, I didn't sleep much.

I was 9½ weeks pregnant and was going on vacation to lovely cabins on a lake upstate (my husband has been going to the same resort with his family since he was 1½ years old). Before we went for a week I thought I would make sure that little heart was beating. I always want my husband there for ultrasounds just in case we don't find the heartbeat, but I had already had around 6 ultrasounds between two of the top perinatologists in the Westchester area, I wasn't expecting a problem.

During the first 5 seconds of the ultrasound the doctor asked me to move to another room with the better ultrasound equipment. He looked again and I see... on the larger screen... two heads... I quickly ask, "Is there two heads?" He said, "That's what I see." They looked so close I immediately asked, "Are they attached?" He said, "That's what I'm looking at". I immediately said, "Look for 4 legs and feet." I saw all four feet and arms, the details of the one little foot with perfect toes floating comfortably was so cute among the horror that they could be connected. The heads were facing each other and it looked as if they were hugging. I could even see their facial silhouettes their perfect little noses and lips. My stomach flipped, and my husband, of course, was in the Bronx at the firehouse. I told the nurse to call him and give him the details so he would not worry the entire 50 minute drive. (Since he is in a job where sometimes there are injuries, we have our own policy to inform each other so there is less worry.) Anyway, she told him that he needed to come but no details. The doctor had never seen this before and he called in the senior OB with over 30 years' experience, he had never seen this either. They were very quiet. Then they called the third doctor... the head of Radiology... again the three gentlemen

doctors were not saying too much and shaking their heads.

They all agreed that this did not look good. They all were in agreement that they were attached. The sweet nurse held my hand and stayed with me. When they were done I called my husband back and told him that there are two babies and they might be attached. He had thought I had miscarried. They gave me a private office so I could use the phone and wait for my husband. When he arrived I asked the nurse to pull up the sonograms so my husband could see. I asked the ultrasound tech for pictures and she didn't want to give them to me, the nurse called the doctor and he gave them permission. I was on the verge of flipping out on her. It was my right to have any info in my file. I needed those pictures. Within one hour we were at my old perinatologist's office about 40 minutes south of us. She has a much softer way and told us to "slow down" that at 9½ weeks the babies don't move very much. She also informed us that even if they were not attached that they are monoamniotic twins and it is not a good situation. She said the best-case scenario would be that I would deliver the twins at 7 - 7½ months and that it is risky. She also said to go and have a wonderful time on vacation and when I returned we would see much more by ultrasound.

Well I could not wait the week and ? . My male perinatologist had gone through Harvard Medical School and he told me that he knew a wonderful doctor who was the pioneer in diagnosing Down Syndrome by ultrasound in Boston. He made us a great appointment for Monday (three days later). We decided to go to our cabin for the weekend and leave for Boston from there. That whole weekend all I wanted to do was speculate and talk about the situation. My husband on the other hand did not. He thought that we did not have enough information. He was very intent on waiting until Monday. (I was alone during the first scary ultrasound and I was convinced, as the doctors were that we had conjoined twins.) Well, we went to Boston and she

gave us the bad news that one could not survive with out the other and there was no possibility of a happy life for them. My husband knew then what I already knew. We were advised to terminate, that there is no hope, and to try again. They all said that this was like getting hit by lightning and that it would not happen again.

Well, my heart was worse than ever with the anxiety adding to the already pounding and skipping beats. While in Boston I saw a cardiologist, then again I saw my own when we returned home after Labor Day weekend. More doctor appointments and then the appointment for my "D&C" (I refused to call it termination). I knew that I was making a sound decision that there was no hope of having twins that could run and play and eventually have private relationships even if we sacrificed one, the other couldn't survive. I also had a 5-year-old boy who was starting kindergarten the same week that I had to consider. What if we went through with it? The large medical costs and getting ramps for a wheelchair put in etc. Our only logical option was to terminate my sweet babies. I would have gone to the ends of the earth to make this work but it could not. I was OK holding it together trying not to fall in love with the sick babies growing inside me. We Made the Appointment for Tuesday morning. I thought I was OK, a little angry at everyone for no reason, but ok. We were parking the car in the hospital parking lot and I started to cry. I could not stop. I dragged my sobbing self with a very silent, calm and supportive husband holding me. I was terrified. I was having phobic aversion to any procedure especially this one.

Well, I came out of it remarkably well and went home. Those nights became the problem. The thoughts of did they get everything, maybe I would find that perfect little foot that was left behind. Crazy haunting thoughts raced through my head. I am all for science and having them take pictures of the babies and studying them for future successful cases. I then thought of our

little babies floating in formaldehyde on some professor's shelf for eternity. Do I want them back? Where would we bury them, and could we get them back if we wanted to? The questions are endless. My husband thinks I might be going too far. His thinking is that the doctors are now guiding us they know best how to handle it, move through the sadness, recover and let them go. My doctor is away now, his colleague has told the lab to do nothing with the babies until he arrives back home in a week. I have no idea what to do.

It has been 5 days since the procedure. I have developed a bad cold. I feel like I have been hit by a truck. Not so much from the procedure, but from the sheer tenseness of my body. My husband couldn't believe the state I was in. I have never felt more sore in my life. It was as though I had been wrestling a large man for hours. The current condition of my body is pathetic.

Update: It has now been about three and a half weeks since the procedure, I had since talked to the doctor and he explained that his main concern was for me that and he carried out the safest procedure for me. I'm satisfied with this knowledge. I am slowly mentally getting better, but my whole system feels not quite right. My thighs are surprisingly MUCH bigger than they were and I simply feel tired. Hopefully, I will get into better shape and feel better all over.

Brenda

<http://www.climb-support.org/html/story.html?bothoral2js&myconjoinedtwins>