

We lost our son, Jonah, on May 16th, 2015. My husband and I together, with six highly educated doctors, chose to terminate our pregnancy for medical reasons—to have an abortion. This is Jonah's story.

My husband, Justin, and I have been together for almost 14 years, married for almost seven of the 14. We began trying to expand our family after about a year and a half of marriage. We tried on our own for a year and decided we should probably seek some help. We made an appointment with our OB, got a diagnosis of PCOS and tried one round of Clomid. Lo and behold, we got pregnant our first round with our sunshine boy, Jude.

When Jude was about a year and a half, we decided we wanted to try for another baby. We tried on our own for three months before going back to the OB to get Clomid. We presumed we would get pregnant right away, just like with Jude and our first round of Clomid. I took the Clomid and had blood work, but we were told no ovulation occurred.

We were told to wait for a period to try again. It never came. At the doctor's direction we took a pregnancy test. The test was negative, so I was given progesterone to start a period. After another week and still no period, I took another test at their request, and it was POSITIVE. Shocked was an understatement.

I was nervous and thinking it was a false positive, but we did blood work and confirmed that we were about 5 or 6 weeks already. We waited until 10 weeks to do an ultrasound to confirm, and everything looked great. We had a healthy singleton baby and sac! We waited to let everyone except family know until about 13 weeks. I didn't feel sick (I was very sick with Jude) and I felt the baby move early. My blood pressure was up, but was holding.

I remember thinking how I've always heard every pregnancy was different, but EVERYTHING felt different; like I had never been pregnant before. Around 13-14 weeks, I started bleeding a bit, not a lot, just enough to cause concern. I immediately called my OB and she told me to come in for peace of mind. We did an ultrasound that same day and everything looked healthy and fine. She said not to worry, but I did. I thought to myself, *"This isn't right; I didn't bleed with my first pregnancy."*

I started feeling nauseated and getting sick quite a bit. I felt something wasn't right, but still kept myself as well as I could with eating healthy and making sure I got plenty of rest. The bleeding eventually stopped around 16-18 weeks. The baby's heartbeats were good at each appointment.

We went in for our 20-week ultrasound around 21 weeks and took Jude so he could see the baby. We chose not to find out the sex, same as our first pregnancy. We were extremely excited to take Jude to this appointment, knowing that we would see the baby on the screen and he would start to understand more than he already did.

During the ultrasound, the tech kept telling us the baby wouldn't move much, that she couldn't get good measurements. I remarked that I thought that was "weird." She was the same tech that did all of Jude's ultrasounds so I felt comfortable asking if everything was okay, knowing she would tell me yes, just like she did with Jude.

My heart sank the moment I asked her how the baby looked she said, "You're meeting with the doctor today? The doctor is going to go over everything with you." I remember instantaneously thinking, "*something is wrong.*" I wanted to get out of there as fast as I could. She did a few more measurements, printed a few pictures, and sent us to the waiting room.

As soon as we sat down, I said out loud what I already felt, "I think something might be wrong." My husband tried to talk me out of it, to reassure me that maybe it was just an off day for the tech, but I knew something wasn't right. I couldn't help but feel concerned.

We sat down with our doctor and she asked how I was feeling. I told her pretty well, but a little sick and so unbelievably tired. As a mother herself, she empathized, and then she asked the dreaded question, "Did we do the genetic panel earlier on in this pregnancy?"

I was cautious and said, "No, remember, we always said it didn't matter, and if you saw something concerning then we would," as we did with Jude. Then she really said it, "Well, I looked at the ultrasound. It's concerning me."

I immediately looked to my husband and his eyes were huge and dark and scared. My eyes shot to our healthy, thriving two-year-old and I immediately started crying; I was scared. I looked back at her and slowly said, "Oooookaaaay?"

She responded, "It looks like Spina Bifida, and I'm not sure of the severity. I want you to go to the perinatal center at the hospital to get more testing done right now." My first thought was *okay, I know about Spina Bifida, I know people who lived into their 40s with this and could walk.* I was talking myself into the best-case scenario.

She asked me if I knew anything about Spina Bifida. I practically shouted yes at her and told her I know someone living a full life with a Spina Bifida diagnosis, trying to will it to all be okay. I cried before we left and she sat with us. We discussed how there are so many options for Spina Bifida now and that they could possibly repair it before the baby was even born.

I was hopeful but scared when my husband, our two year old, and I ran out of the office as fast as we could. I called my parents and my sisters on the way to the hospital. I was trying to find anyone to come pick up our son so he could eat some lunch and not have to feel all the hurt we were experiencing.

We arrived at the perinatal center and they immediately took us back. My mom and dad met us there and my dad took our son home and my mom stayed for added support. Two hours in and we were still doing the ultrasound. I actually remember thinking out loud to my mom, *I wonder how I will breastfeed a baby with Spina Bifida?...*

How naive of me! We became comfortable enough to ask our tech if she was comfortable sharing what she was seeing. She immediately said, "I feel comfortable answering some questions, but they are going to want you to do an amniocentesis today." I knew then that it was much worse than I could even imagine.

She took a break so I could use the restroom and said she would be back with the perinatologist on call. I asked what type of doctor we were getting. I know that seems strange, but I wanted someone compassionate, empathetic, but who would tell me the

facts. She told me there were two doctors and the one she was going to grab was exactly what I was wanting and needing.

An eternity later, she came back in with the perinatologist. The doctor sat down and said what I knew, "So, I know you know about the Spina Bifida that your OB found, but, this is bad. Really bad. I'm so sorry." She reached out and grabbed my hand. I started shaking and burst into tears. A few hours ago we were so excited to see our new baby on our ultrasound with our two-year-old and now our life was falling apart.

She waited a moment for me to quiet a little so she could really let us know what was going on. She went on, "This baby has *very* severe Myelomeningocele (Spina Bifida). Unfortunately, it is inoperable. It starts at the level of the heart – it's basically the whole spine. Amniotic fluid is so toxic to the spinal cord, and your baby's spinal cord is being bathed in it all day, everyday. The brain stem is being pulled back and down through the skull, which is pulling the skull into a lemon shape, and causing the front to be very sunken in. There is a lot of fluid on the brain already. The left hand is cleft, and we think the left foot also has a deformity, but we cannot get a good picture of it to tell. We also think there may be a hole in the heart."

During all of this we took frequent crying breaks. My husband and I asked about prognosis for life. I remember hearing "poor prognosis for life." Up until the two hours previous, I never would've considered a pregnancy termination, ever. But with her going on to say this baby, *if it made it to term*, and it was an gigantic if, would need around-the-clock care until its life ended, and that it would be early in life; that there would be surgery after surgery, and SO much pain. That essentially, our child would be born onto life support. Again, *born onto life support*.

I immediately told my husband I didn't want our baby to suffer and he absolutely agreed. I felt immediately we were making the right decision. I also felt immensely guilty thinking about us as a family and how all of our lives would be changed too; the quality of life would be poor for everyone, not just our sweet, imperfect baby. The whole tone of our conversation was wrapped into one thing she said to me at the end of our questions and answers. "Kadie, I want you to go get a second opinion, because at this hospital, we cannot provide certain services, and they can if you choose so. Also, I need you to understand that you are on a time crunch: you're already 21 weeks and Missouri law sates you only have until 21 weeks and six days; after that, you have no choice but to carry to term. If you choose to carry to term, we will do everything we can to keep this baby comfortable and will be with you every step of the way whatever you choose."

She suggested we move forward with the amniocentesis; per her recommendations we did. I remember the procedure vividly; the sweating, the intense cramping, trying to stay completely still, all while still breathing. The doctor actually said, "You're such a rockstar." Through tears I said, "I don't feel like one." The genetic counselor came in to talk with us and she mapped out our genetic family history and asked if we knew what path we were choosing. I told her we had made our decision, but I couldn't help thinking I was murdering my baby. She told me that her mother, who is very anti-abortion, would make the same decision in this instance. It didn't take away the guilt, but made it easier to bear.

*Abortion* – I hated that word. I didn't feel like I was aborting my child, I was terminating due to a diagnosis. It actually angered me to hear the word. It felt wrong, and termination made it more compassionate in my mind. We left the hospital two hours after their maternal fetal medicine office had closed. The doctor we saw, genetic counselor, and ultrasound tech all stayed later with us until we were ready to leave.

My husband and I went home and cried. I remember calling my boss at the time to let her know what was going on and that I wouldn't be at work. She understood and said I was "making the best choice." Working in the health field, and being a doctor herself, it gave me comfort knowing she would do the same. I never considered myself pro-choice before this.

Do I honestly think I had a choice? No. There wasn't a "choice" to make. Having already had a healthy, thriving two-year-old, there was no way on earth I would let my child suffer the way this doctor was describing for any sort of life my child *might* have: to never walk, talk, have any sort of brain function. There would be no playing, singing, thinking – nothing. What kind of life is that? Would you make your child suffer this way, make anyone suffer this way? I wouldn't. I didn't.

We followed up with the second opinion two days later since it was Friday when we found everything out. Those two days over the weekend were unbearable. We kept talking about it over and over and thinking and talking and more thinking. I just wanted it to be over. Our appointment was pretty early in the morning. The two maternal fetal medicine doctors we saw started the ultrasound with, "We know this is very difficult, but can you tell us why you are here for our records?" Through tears and broken words I said, "I want to make sure I'm making the right decision..." The doctor nodded, empathized, and we began.

After an hour and a half, they (the maternal fetal medicine group as a whole) decided to confirm everything that the first and second ultrasound found, but they found more. They said our baby was paralyzed already due to the severity of his Spina Bifida, that the left foot was indeed cleft and clubbed, the heart was on the wrong side of the body. There was a HUGE scoliosis, and a hump on the back up by the neck.

We were stricken again with such sadness. All of the hopes and dreams for our child went completely out the window, even if we still had a glimmer of hope of some kind of normal life for our child.

Knowing our minds hadn't changed about the termination, they asked if we wanted to meet with the termination doctor, and at first, I didn't want to. I felt like everything was moving fast and I needed to breathe. Fight or flight was kicking in, but I also knew that we only wanted our child to feel love.

I remember the one doctor, who I wasn't too fond of, actually said to me "I cannot tell you what to do. I can only tell you what I find. You have to decide." I asked them to give me five minutes and check back. I remember getting a call from the genetic counselor during this five minute time and her stating that the initial pull from the amniocentesis was clean. There was no genetic reason for what was happening to our baby.

They checked on me when the time came and my husband and I agreed to meet with the doctor and go over our termination. This doctor exceeded my expectations. She started off by saying that she looked over everything, and said we were "doing the most compassionate thing" for our baby. I needed to hear that. I absolutely needed a medical professional to tell me I was doing the best thing I could given the circumstances.

She explained, in great detail, the two procedures – labor and delivery or a dilation and curettage. We chose to labor, because I wanted to hold our baby. I knew I would need that for closure and to remember what was so perfect about him, not his multiple diagnoses. I wanted to hold our child and kiss him goodbye.

Because there was a 72-hour waiting period, and we were already into our 21<sup>st</sup> week of pregnancy, we went ahead and signed the papers. They stated we had heard the baby's heartbeat and saw the baby on ultrasound, but the doctor made it clear that we could change our mind at any time.

I asked her how she could do what she does on a daily basis, saying it must be so hard to think about all day. She replied that it wasn't, that she knew she was giving families peace of mind and helping them to make hard decisions that no one should ever have to make.

We asked about burial of the body and she told us they do a mass cremation of the babies and spread their ashes in the garden there at the hospital or we could do a private burial or cremation. I decided I would like to privately cremate our baby, so he could be at home with us where he belonged. We asked if we could donate our baby's body to science but were denied because it is considered illegal in Missouri. I remember being confused and shocked that I wasn't allowed to donate his little body so that others could learn from him; to know what caused all of this to occur. It was also discussed that we couldn't file for birth or death certificates.

We went home that day and decided to pick out names that meant something to us, or had some meaning, as this would be a special baby and we still didn't know the gender. My original OB called me at home on Wednesday to talk about what was happening. I really appreciated her reaching out and touching base to check on me and making sure I knew she was still there for support. We talked about our decision to terminate and she, too, told me I was making the best decision for our family and our baby.

By this time, we decided it was time to let more of our immediate family know what was transpiring. We called our respective siblings one by one and notified them of our baby's diagnosis and our decision. We were met with understanding and love.

On Thursday we went in to see a different doctor that would give me a pill to soften my cervix. I remember waiting forever and intentionally sitting in an area no one would sit in so I didn't have to see these happy, pregnant women and their bliss. I had to sign some papers, take the pill in front of the doctor, and keep it down for at least 15 minutes.

During the 15-minute wait, the doctor told me that he, too, looked over all of the ultrasounds and findings. He stated that our baby had a "0% chance of life" and that we were doing the "compassionate thing" for our baby. We talked about the word abortion, and how it is a broad word. He informed me that I would just go to labor and delivery the

next morning, and we would begin. Friday morning, we reported to the hospital to begin induction. As expected, we didn't sleep at all.

In one week, we found out, made our decision, and now it was time to birth this baby and say our goodbyes.

I was devastated, heartbroken, guilty, gutted, angry... so many things. I was scared to get started. Having been through labor before, I knew what to expect physically. The termination doctor told me the hospital could give me things to remember my baby with. My first nurse got me a recording of the baby's heartbeat and put it in a stuffed frog. She also gave me papers of my contractions once they started and then unhooked me after we got a few.

I felt numb, like it wasn't really happening, and that our baby would be born and would be fine and we would go home. We began with changing me into a gown, and getting me as comfortable as they could. My mom asked what she could do to help me. I asked her to bring some flowers along to make the hospital room more peaceful and have something beautiful to focus on. We also had an ultrasound picture of our beautiful angel in a frame there as well as a family picture with our two-year-old in it.

A doctor came in and inserted some tablets to get our induction going. They informed me they wouldn't be checking me and would let me progress on my own. They placed more tablets every so many hours. After about two rounds of tablets, I no longer felt the baby moving. I knew at that point our baby had probably passed. It almost gave me comfort knowing that he wouldn't have made it through delivery, or full gestation. It made me realize how sick he really was.

I really started to feel contractions at the 8-hour mark. I asked for some pain medication and they gave me Dilaudid. I wanted to escape and not feel anything. After a few hours on the pain meds, I started vomiting and dry heaving. The pain medication started to not work as well as it had been.

Around the 30-hour mark, I asked for an epidural. Unfortunately, just like with my first birth, it didn't work properly, and I immediately needed to push without medication. When I felt the urge to push, I freaked out. I yelled to my husband and mom to call the nurse over and over again, I kept saying it, even as she was walking in the room with one of the doctors from our second opinion ultrasound.

There were no stirrups; there was no yanking, no pulling. I held my husband's hand as he cradled me, with my head buried in his chest, and I held my most favorite nurse's hand. My mom was crouched next to the bed holding my leg to comfort me. I sobbed and said I wasn't ready yet. Even though we knew he had already passed during labor, I didn't want to let this baby go. The doctor told me to push when I wanted to. I went ahead right away. I pushed out our baby in one push. I waited to hear a cry, but remembered there wouldn't be one. I yelled, "DON'T LOOK" to my husband and my mom. I wanted him wrapped before we all saw him because I was scared of what shape his body would be in due to every diagnosis we had heard in the week leading up to this.

Very quietly, the doctor said, "It's a boy." I immediately asked if he was alive, to which my nurse just shook her head "no." Our sweet little boy, Jonah Michael, was born fully

intact, not breathing and with no heartbeat, on Saturday, May 16th at 3:50 p.m. He was bathed by love and a peaceful quietness. There were silent tears from everyone in the room.

My nurse quickly wrapped him so we could hold him. My husband reached out his arms and she passed our son to him. My placenta wouldn't detach so I ended up having to also have a D&C. We spent the next 24 hours with him; holding him, taking pictures of him, telling him how sorry we were that because of his diagnosis, he wouldn't ever have the life his older brother did.

I was terrified to unwrap him. My nurse asked if I wanted to bathe and dress him. We had a priest come in and baptize Jonah. I remember him using a seashell as big as his little body to hold holy water in. I was afraid I would harm his little body for some reason, so I asked her to bathe him for me. She did and also took some keepsake pictures for us, and when she came back in, she said, "I know you want to look at his body, but I wouldn't right away." I was so grateful for her being so honest with me.

I did eventually unwrap him with the doctor and my mother present; my husband didn't want to see. I saw Jonah's numerous skull and facial bone malformations, I saw his skull shape, I saw a clubbed arm with a cleft hand and foot, I saw both clubbed feet, I saw his stunted growth and a huge tumor off the side of his neck. I wrapped him back up and hugged him the entire night and into the morning. The next morning, we all took turns saying our final goodbyes and the nurse wheeled me to a special room that he would be placed in until he went to the morgue. She gave me the knitted blanket and hat that he had worn. I asked for the actual hospital blanket that was touching his skin and she went back in and got it for me. We asked the nurse to please give out the flowers we brought with us to other mommas in labor so they could enjoy them while bringing their live babies into this world.

That afternoon, the nurse wheeled me as my husband and mom walked beside me out of that hospital. As we were waiting for my husband to get our vehicle, the doctor that went over the termination with me pulled up, got out of her car and hugged me as I wept into her shoulder. I will never forget her or anyone else we came in contact with during this extremely difficult time.

My child died in my womb, filled with peace and love while not feeling any pain. At the end of each day, I'm the same as any other mother who has lost a baby. Heartbroken. Lost. Bewildered. I don't think this will ever change, but other mothers who have been through similar experiences tell me that it will become easier to manage over time.

I'm thankful every day that abortion was available to my family and I will never stop telling Jonah's story. I hope that by sharing Jonah's journey some who are anti-choice will see that abortion is never black and white – there is a LARGE grey area that MUST be discussed.