

An Orange Socks Story- Casey: Limb Difference

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I'm very appreciative of Casey and her willingness to have an Orange Socks interview by phone about her experience with her son, Owen, who has limb difference.

Gerald: Casey, thank you so much for speaking with me about your son, Owen. Can you tell me when you found out that he had a limb difference?

Casey: My husband and I found out that we were pregnant near the fall of 2015, and we were just overjoyed. It took us a while to conceive, so we were excited for the anticipation of this baby. I'm relatively young, with no previous health concerns, so up until our anatomy ultrasound, I had a perfectly normal pregnancy, no risks, no concerns. We went in to our anatomy ultrasound really excited about the sex of our baby, and I was thinking the whole time that it was going to be a girl. I was so excited that I was calling the baby a girl's name, I was just really so sure. We were so excited that day. I remember being lively and joking, and the mood and the feeling was so good. We were just so excited about the birth of this baby. We went into our ultrasound with our sonographer, and she told us that we were having a son. I thought that was going to be the biggest news of the day, but it turned out there were some things that were concerning that she couldn't find. A lot of times, I feel like families experience real hardship in that initial ultrasound when they get a diagnosis, because there's sometimes a conflicting report or certain things that the sonographer can't tell you without a doctor's approval. We were just so blessed that day, the Lord really was with us in that moment because she was pure joy in the midst of an incredible trial. We knew that something was wrong as she kept coming and going from the room. I couldn't see Owen's hands the whole time, and I just knew it was a mom's instinct down in the deep of my gut that something just wasn't right. Eventually, our sweet sonographer told us after I loudly asked, "Can you please just show me where his hands are? Please show me his hands." She said, "I can't find his hands." She was confirming what she already knew, and she had my doctor on hold waiting to talk to us about our son's diagnosis. That day still leaves me feeling a lot of pain, though thankfully, every day it dwindles. We just came up on the year anniversary of finding out about his limb differences, and that was a difficult day. Our doctor was the sweetest ever, and she took good care of us through the whole duration of our pregnancy, but on that particular day, she explained to us over the phone what was going on with Owen and what limbs were affected. Unfortunately, at that appointment, they couldn't even really give us an idea of the viability of the pregnancy, because up until that point, my pregnancy had been perfectly normal, and there was no need for them to monitor his growth and development. They were really unsure, they had never dealt with a limb difference to this extent, and they didn't know if Owen was growing right or if he would make it to full-term. That was a really scary day for us. It was a big blur, and there was a

lot of shock involved. She spoke with me on the phone, and I just remember crumbling to the ground, feeling completely crippled in pain. We were sent to a specialist that day to get follow-up information about the baby and about what we could expect. That was a really hard day, and so were the days that followed.

Gerald: What type of advice did they give you at that time?

Casey: I'm not sure if I can really recall the specific advice. I think one of the biggest blessings that was given to us that day was then our sonographer knelt down on the floor in front of me, held my hands and let me cry, and she cried with me. She told me, "It's going to be okay. Everything is going to be okay, and your baby is going to be just fine." That was really something I felt that was going above and beyond for a medical professional, to come along side me in that moment of utter grief and tell me everything is going to be okay, and I'm here with you in this moment that is so painful. When I think back to that situation, I think that if I were in her shoes, I would have wanted to be far away from that room. There was so much pain in that place, and if I were her, I would have been hiding on the other side of the office if possible. She did something that was incredibly difficult, and she sat there beside me, cried, held my hands and reassured me that we were okay, that we were safe, that our baby was going to be okay, and that we were going to get through this. A lot of the other parts of that day escaped me because of the pain, but I will always remember the love that woman showed, more than even the love of our doctor. I think that a lot of times their immediate gut reaction is to say, "Well, you still have time to think about your options and to abort this baby if that's your choice." I think our faith is so grounded that it took a lot from what our doctors needed to hear, and that wasn't our choice. They were so supportive and so loving in that moment, just reassuring us that we would all get through it together.

Gerald: That's terrific, really terrific. Owen was born 10 months ago, what was that day like?

Casey: Well, when Owen was born, we had a scheduled c-section. He was breech for the majority of my pregnancy, and at first, I was just really upset at the thought of having a c-section. I had my thoughts and plans for a birth, but the way things worked out was that if my doctor wasn't on call, then I had the chance of having a number of other doctors, maybe 30 other doctors, and to me that felt really scary, too, because I had walked this road with this doctor who I had such a good relationship with. She had taken us through this immense trial of watching this baby grow and develop, and at every subsequent ultrasound, we would find that he was indeed growing and that he was indeed healthy. It was such an encouragement every time. She had been such a pillar of strength for us through all this when we were really digging to find strength, so when it came time to figure out what we were going to do for Owen's birth, it was almost a relief when we found out that we were going to schedule this c-section, because that was my assurance that this woman who had walked me through what was probably the most difficult situation of my life was going to be with me to deliver my baby. We had our scheduled c-

section, but I was really nervous. I mean, I was so excited to meet this baby, but I loved being pregnant, I loved the whole pregnancy. It just really sat well with me, so I was thinking that I didn't want this to end. I was so nervous about meeting this baby. What if I meet him, and the only thing I can think about are his differences? I didn't know what to expect. I was anxious and concerned, so when we finally went into the operating room and had the c-section, and Owen was delivered, and they brought him over to me, all I could see was Owen and his genuine perfection and how precious of a baby he was. They laid him on my chest, and it was the best moment of my entire life. I didn't even notice his differences, and my husband and I sat in our hospital room the following day, and he said, "I don't even see anything but Owen, this is our baby, and everything is perfect with him, and he's just the way that he is supposed to be." From that day forward, that's how we've always felt, this is just our Owen, and he's perfect and brings us so much joy.

Gerald: That's wonderful. What have been some of your greatest challenges with Owen?

Casey: I think the biggest challenges were probably during my pregnancy. I had to work through a lot of grief and a lot of sadness surrounding his diagnosis, and I think that had much more to do with my own heart than it had to do with Owen. It was a true blessing to have the second half of my pregnancy to prepare for him in an emotional way, and that was really challenging. I had a lot of really hard days, not knowing what to expect, not feeling like it was real. At that point, we hadn't connected with anybody who had walked through similar experiences to ours, so I felt really lonely. I wondered how this could possibly be happening to our family, and that was really challenging. Getting up the confidence and the courage to talk to other people about Owen's diagnosis was extremely challenging, too, because I felt like I was in such a place that I didn't have the information that I needed. I didn't have the confidence to speak without crying. I didn't know what the future would hold or what to expect, and, that was really challenging. I genuinely feel like since Owen's birth, we've had the opportunity to experience him as a baby just like any other family would, and that has been such a joy. We do have some challenges where we have to have some hard conversations with people who don't understand limb differences, or the anxiety of being a first-time parent and having your child out in public who is not typical, that can be kind of anxiety-driven. For the most part, it has been wonderful just having him here. The anticipation of Owen was much more difficult than actually having him in our day-to-day life. That has been the easiest part of the journey thus far. We do have extra things that we have to do, like an occasional specialist appointment or routine physical therapy and occupational therapy with him, but to us, that's just become a part of our routine. I don't think we'd change it for anything at this point.

Gerald: So, what have been the joys that you've experienced in having Owen?

Casey: It's really interesting, because the joys that have come with parenting Owen began when I was pregnant. I had this really selfish kind of mentality that I just

wanted to be normal, I just wanted to have this normal family and fit in with all my friends who were having babies. Prior to our pregnancy, we had been foster parents, and we still are, so we were fostering other children. We were parenting children who were toddlers or preschoolers. Our family already didn't look "normal," so I thought, "Wow, now we are pregnant, now they have an opportunity to understand us better so maybe they'll want to be our friends again." That was really a selfish mindset on my part, and I thought this would be such a burden. I felt like we had already burdened our family with foster care, which was, in fact, a joy in and of itself. So, I thought that now we're bringing this baby into the world who has this limb difference and potentially other health concerns. I just felt like I was hurting my family, or that this was going to be something that is negative. Now having Owen in our lives and being able to share him with people is the greatest joy that I think anybody can experience. Everyone who comes in contact with Owen is better because of it. The way that he's worked through the hearts of people that we interact with, and not people that we necessarily interact with on a day-to-day basis or that we have a close relationship with, but through our story and through Owen's story, hearts have been changed in ways that I could have never imagined. Being almost a gatekeeper to Owen. Having a small baby and having people communicate to me about how he has impacted their lives has been such an honor. It has been completely humbling, hearing how this small baby and how our perseverance and our joy in the midst of something that people could be really sorrowful has changed other people's perspectives and hearts. It's just overwhelming to know that this small baby was sent here with such significance, and I know that his presence here on earth is more than the average person, that he was sent here to do things that we can't even imagine. That has been humbling, because how was I chosen to be the mom of this incredible human?

Gerald: That's super. If I were to come to you just having received the word that I had a child in utero who the doctors or the attending medical people have diagnosed with a limb difference, what advice would you give me?

Casey: I think that if a parent were to come to me knowing that their child was going to be born with a limb difference, I just would want to wrap them up in a hug, because I know the deep hurt that can come with news like that. I would want to show them how beautiful life can be, how capable our kids with limb differences are, how much joy they can bring and how they can truly accomplish anything that they want to. I wouldn't have thought that, and I wouldn't have expected that, being the one on the receiving end of the news before Owen was born. I feel like having the opportunity to share the story and to share about other families who have been impacted by limb differences and other adults who are so successful and so capable, sharing about their accomplishments and the fullness of their lives is something that I would want to pour out to other families. It felt like it was really difficult for me to find people to connect with or even to find people with limb differences to the extent that Owen was going to be born with limb differences, so I really feel like that is something that I'd want to share with the family walking through a similar journey. Everything is going to be more than all right, your life will be much more

incredible with this baby in it. You will not feel this sadness once you have the opportunity to meet your child.

Gerald: You had issues to deal with and to adjust to prior to Owen's birth. You mentioned several things that you personally went through, that you wrestled with, and the difficult times that those were for you and your husband. Now you have this child, and he's 10 months old. After experiencing what you experienced, was it worth it?

Casey: Oh, yeah, I'm not sure exactly the question of it being worth it, like going through it all, but if you mean would we do it all again, I would do it all again in an instant. I wish I would have known then what I know now, because it would have put me in a better place the second half of my pregnancy. Don't get me wrong, I loved being pregnant. There were so many days filled with joy, but there were also so many scary days with that anxious anticipation of what our life was going to look like and what the future was going to look like for this child. How is this going to impact our day-to-day life? Are we going to be able to give this baby everything he needs? I wouldn't change it for anything. Owen is the best gift I've ever been given.

Gerald: Super, Casey, thank you for taking the time to speak with me. It was an honor to meet you by phone and to hear your story and Owen's story. Thank you very much.

Casey: Thank you.