

An Orange Socks Story – Mandy and Steven: Hydrops Fetalis and Bilateral Renal Agenesis

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: It is my privilege to have an Orange Socks interview with Mandy and Steven. Mandy and Steven already had four girls and were excited with the prospect of having a little boy. That excitement quickly changed when they discovered the baby had multiple issues including hydrops fetalis, enlarged heart and bilateral renal agenesis. They were offered the option of an abortion twice during testing. Thank you, Mandy and Steven, for speaking with me. Tell me how your journey down this road began.

Mandy: At 16 weeks, we went to one of those paid places to find out your baby's gender early. Since we had four girls, we were really excited when we found out we were having a boy. Super excited! But then, at the 20-week ultrasound when you normally find out the gender, we already knew, so just me and my oldest daughter, who was nine at the time, decided to go together and see the baby. At that ultrasound at my doctor's office, they couldn't tell if it was a boy or a girl. It was taking a really long time, and the technician told us we had to see the doctor. My daughter and I were sitting in the doctor's office when he came in. I love my doctor, but he came in and said, "There is something seriously wrong with your baby." It was just a punch in the gut. The next day, they scheduled me with maternal fetal medicine, and we went together. At that appointment, they told us he had a condition called hydrops fetalis, which means two cavities in the body are filling with fluid. They also couldn't find some vital organs in his body. They pumped us with all that information and then at the same appointment, they also...

Gerald: At the same time that they learned the extent of their baby's issues, Mandy and Steven were given the insensitive and confusing option to abort the child.

Mandy: They told us, "You have the option to terminate," and we sat there for a second just...

Steven: Kind of in shock. Denying. To me, it's amazing that they would even ask us this.

Mandy: Especially when they gave us all that information at the same appointment. They didn't even let you think about, though I guess you could have thought about it. It was like everything was thrown at us, and then they ask us that question. We looked at each other for a little bit and then we said, "No, we want to keep going."

Gerald: This was at 20 weeks?

Mandy: 20 weeks, and the maternal fetal medicine doctor told us that he would be stillborn. He was not going to survive. We asked if we could do testing, we wanted genetic testing done. We wanted to know what was happening because they didn't know. They just knew he had hydrops, but they didn't know about his organs, because that shouldn't affect his organs. So, we continued with testing. We saw cardiologists, we had an MRI and genetic blood testing.

Steven: At the 20-week appointment, they realized that his heart was enlarged, so that's the reason we went to the cardiologist.

Mandy: After a week's worth of testing, we found out that he had no kidneys. It's a condition called bilateral renal agenesis, and is very rare. So, if one didn't kill him, the other one was going to. At that time, we were again asked or told that we could terminate, "He's not going to live." We decided to see what happened. We wanted to meet our baby. Even though they were telling us it was a good chance he was going to be stillborn, I was going to try and do everything in my power to meet that baby, whether it be for a minute or an hour. It was really important to me. We were confused, and we didn't even have time to

absorb what was happening. We were just told all of this horrible information, and then they asked us to abort our child, who has a heartbeat and was moving. He came on his own at 33 weeks. I should have said that they also told us that when he was born, he was going to be deformed, very deformed. His limbs and everything, so we were trying to prepare our children for this.

Gerald: What was the result?

Mandy: It was a really crazy few months, but at 33 weeks, he was born. He was perfect. He lived for an hour and a half. All of our girls got to hold him alive, and we did too. It was the total opposite of anything they told us could happen. It was amazing. As sad as it was, that's one of the happiest days of my life. We have four girls who are now ten, five, four and two. It was amazing to me because I thought they would be scared. But they loved him, and in every picture we have, they are smiling at their baby brother and just loving on him. My oldest daughter understood it a lot more than the others. She was pretty sad when she got there because she thought he had been born stillborn. But I was able to take her hand, and I placed it on his heart, and his heart was beating, and it just changed her whole mood. I have a picture of that. We still held him. The nurse came in and checked his heartbeat for a while. One of us, I think my grandmother, was holding him. She just kind of gave me a nod that he was gone, and we just kept going. My girls still hugged him and loved him, and we still hugged him and loved him and took pictures with my girls and then my aunt, my uncle and my grandmother and actually then a friend who also came.

Gerald: How did you prepare your family for the birth?

Mandy: I should say we were completely honest with everybody from 20 weeks on. I told my girls that he wasn't going to survive when we found out.

Steven: Some days were hard.

Mandy: We're religious, and we were able to bring that religion into what we were telling the girls, and they're okay. They know where their brother is, and it brought us really close together.

Steven: Yeah, really close together.

Gerald: Did you have any, "what if?" moments?

Steven: That would be me. I'd be always wondering, "what if he kept going?" When we went to the hospital, she kept having these pains, and she was like, "No, no, I won't go," and we ended up going later on. I always wondered what if we just waited and they went away. Would we have gotten the chance to meet him alive? Would the result have been totally different? I'm really glad she acted on being able to go because that was the thing that we both wanted, most importantly, to meet him alive.

Mandy: That's what they told us was going to happen. I did things that the doctors thought were silly, but I insisted. Like, I did the shots for his lungs. I don't even know what they're called.

Steven: It was a steroid shot.

Mandy: Yeah, and when I called the doctor and asked about those shots, he basically said it was pointless. I knew that, you know, but I wanted to do it. I wanted to do anything I could, and I did everything. I did everything.

Gerald: Would you do it again?

Mandy: I would in a heartbeat. It was the best decision for us, for our family, for a minute, or for an hour and a half of his life. I think it's really easy, and really sad that the doctors throw all this stuff at you and

then ask you that horrible question about abortion at the same appointment. I mean, it's horrible. You have so much going on in your head that you cannot make a rational, right decision. I would just encourage people that if you're a research person, do some research. If all you need is to pray, or think, or listen to your heart, do that. Give yourself a minute. Step back and think about it. I think a lot of people are pushed and scared and just kind of react, and if you actually step back and think about things, you realize that they're just medical professionals who know things from books, but miracles can happen. I mean, everything that happened to us was not supposed to happen, and it did! He was alive, and he was perfect, and I wouldn't trade those minutes for anything.

Gerald: What would you tell other parents who are currently in similar circumstances?

Steven: Just don't give up. Medical professionals don't know everything. Everything that we were looking at was totally opposite from what they told us. From the cardiologist who said that his heart would stop, to the cardiologist who told us his heart was fine. Just everything, everything was totally reversed from what they kept telling us. Just don't give up. Do your research and figure out what is best for your family. It was amazing. We got a lot of good time. I enjoyed it.

Mandy: Plus, he looked just like him. He was amazing. It was the most amazing experience I've ever had.

Gerald: I am so appreciative to Mandy and Steven for their honesty and willingness to share this special moment of their family.