

An Orange Socks Story – Sydney and Darren: Alobar Holoprosencephaly

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: It was an honor to meet with Sydney and Darren. Theirs is a spiritual journey, and their decision to continue with the pregnancy is certainly inspiring and courageous. Their baby was diagnosed with alobar holoprosencephaly, a certain fatal condition. They were told the baby may not survive the pregnancy, and if she was delivered, wouldn't live very long. The decision to press forward has impacted all who know them.

Gerald: Sydney and Darren, thank you for meeting with me. When did you find out that your baby had a problem, how did the doctor introduce the concept of abortion, and what were you thinking through this process?

Sydney: I was at my 20-week ultrasound appointment. It's called alobar holoprosencephaly. It's a big term, but pretty much what it means is that there was no separation between the left and right sides of the brain. They found it through the ultrasound. It's very commonly linked to Trisomy 13, so that's what they thought it was at first, but after I took the NIPT test, it wasn't Trisomy 13, 18 or 21. It wasn't any one of those. So, it still could be genetic, we were going to do more testing later, but we just decided not to.

Darren: So, we went to the ultrasound, and the technician was doing it like a normal ultrasound, and then it took a little bit longer, and at the end she kinda turned to us and said, "I'm sorry, but there's something." We found out that it was a girl, and then she turned to us and said, "There's something that's a little different, but I don't know what it is. I'm going to go have the doctor look at something, so we'll be back." She left, and then a few minutes later, the doctor came in, and he said, "Yeah, there's something that's off. The heart looks good, but there's something in the brain, something off that we can tell, and so we want you to go to a specialist. We'll try to get you in as soon as we can. Most of the time it's usually two weeks out just because it's a busy area." But they said, "We'll try and get you in as soon as we can." We got lucky as about an hour or so later, the hospital called and said, "We have a spot that just opened up so you can come in." So, we were able to go in, and the specialist kind of did another ultrasound which took a little bit longer. Once again, he specialized in reading ultrasounds, and he looked at it, and then he went into more detail and kind of explained more things as we were doing the ultrasound. He said, "Yeah, there's definitely something wrong with the brain as you can tell. Usually there's a separation, your baby doesn't have a separation." Then we went into his office, and he went over different scenarios of options. The first option that he brought up was aborting the baby.

Sydney: It was interesting, and I don't know if it's just because that wasn't on my radar at all, but I didn't catch on to that. He was doing it very subtly, I'd say. He'd say, "You know we'll talk about different options. You know you can come back, and we can talk about options that you have." And he just kept talking about "these options," and I can't even remember the word that he said when I was like, "Oh my gosh, he's talking about abortion." But I don't, he was doing it very subtly.

Darren: Subtly and he was going really, really fast, and even when explaining what our daughter had, I felt like he was kind of explaining it really quickly. And at that time, we didn't know if we had a day with her, or if we had a year with her, you know. We didn't know how much time we had with her. After he talked for 10 minutes, he finally said, "It's fatal." And that's when I was like, "Oh wait," like that was interesting. He presented that there was an abortion option.

Sydney: He said, "The baby will not live long after birth."

Gerald: How did you react to this news?

Darren: He presented the abortion option, and it was subtle and kind of, I don't know what the word is for it, smooth. However, the other option was the one that we chose.

Sydney: I asked, "What's the likelihood that she'll make it to birth?" I just wanted to hold her, to see her. He said, "You know the probability is high," but I do feel like the first option he brought up was abortion.

Darren: Yeah, I felt at first, I felt like that's what he wanted us to choose. Like that's what he was trying for, but then I think after he saw that we, you know...

Sydney: We had no clue that anything was wrong. I wasn't even aware the ultrasound was taking longer. Usually the ultra-stenographers aren't supposed to say anything, but we're so grateful that she did because right at the end she said, "I'm so sorry, something's not right with the brain." And, I don't know, it was just shocking. It was not what I was expecting at all.

Gerald: Tell about the delivery, when you had a chance to hold her and the reaction of your family.

Sydney: She came at 37 weeks. We were induced because her head started to get big, and they were worried that I would have to do a C-section if we went full-term. But she went full-term in that she went 37 weeks. They didn't really check her lungs, they were looking at everything else, and she looked pretty much on schedule with my due date, so they thought it would be safe. My parents live in Lindon as well, and so they were able to be there. We went in for the inducement, and labor went pretty smoothly. Towards the end, the baby's heart kept dipping, and that was really stressful to me because I just wanted her, I just wanted to hold her. I'd gone nine months, you know, I'd spent the time creating that little body in there, and I wanted to enjoy seeing her alive. So, they would put fluid back into me, and she did finally come. I still wasn't sure if she was going to make it through birth because sometimes they don't as the labor is too stressful for them. But she came out, and I heard her little sob, and I started sobbing because I was like, "She made it!" That's what I wanted. They took her over and started helping with her breathing because she wasn't breathing very well, and I just tried to tune it out. I think that's the hardest 15 minutes I've ever had to listen to in my life. But the top neonatologist in the area was there, and he helped get her breathing. They put her in my arms, and it was just instant love for her. They moved us to another room, and at first, we just had our parents and my kids there. I just wanted her to meet her siblings so bad. In fact, I hadn't wanted to intubate her at first because I just wanted her life on earth to be loves and cuddles, not having doctors poke and prod her. But when they said, "She isn't breathing, we need to intubate her," I was like you know what, yes, we do, because she needed to meet her siblings. So, we held her, and then his siblings came and some of my siblings came, and they all got to meet her. She lived five and a half hours. I have younger siblings, I'm the second-oldest of 10, and only some of the older ones came because we didn't know what she was going to look like. We had no clue, and I didn't know if it was going to scare anybody, but she was beautiful and my kids loved her.

Gerald: If you would be so kind, please tell me the impact that Grace's birth had.

Darren: I think she blessed everyone's life that she came in contact with. I think everyone who held her was changed. Our two-year-old son didn't really understand at the time, but he talks about her now, and he knows that she's his sister, and our four-year-old loves her to death.

Sydney: When we were in the hospital room, our four-year-old kept saying, "Grace loves me! Grace loves me!" from across the room, and when she came in, she just loved her. She wanted to shower her, her dolly. They had matching bracelets, and she was so excited about that. She couldn't kiss her enough. She just adored every bit of her. Grace's nose was deformed, and she only had one nostril. She had a very large head and her eyes were close together. She wasn't a normal-looking baby, but my kids didn't care one bit. I think they could just feel how sweet she was and that she was their sister, they were just all excitement. It's interesting cause even just that five and a half hours, man, I'll never forget that experience of holding her and loving her. And we were able to get video that we can watch, and I can just remember how sweet she was. But also, it wasn't just those five hours, it was the 24 hours after that, the week after that and ever

since. I thought that it was going to be really weird after she passed away, holding a dead baby. I thought that was going to be really hard, and it was so interesting cause there was still so much comfort in just holding her little body. I still felt very much at peace about the whole thing and she was still my little baby that I was holding. Even my 17-year-old brother came and helped dress her for burial, and you'd think that for a teenage boy, emotions are beneath him, but after we left, he looked at us in tears and said, "Thank you so much for letting me come. It was definitely a different experience holding her." He wasn't able to come to the hospital and even though it was six days after she had died, he got to hold her, and he still said it was different holding her, saying again, "Thank you so much."

Gerald: Do you regret your decision?

Sydney: I don't regret it one bit, not aborting. I mean if I had, I can't imagine how I would be right now because I received so much comfort in the fact that I held her, and I have pictures of her around the house and video I can watch. I'd say I was the one carrying her for nine months, and for half of that time, knowing that she wasn't going to live long, or that she may pass at any moment really, I knew that I had to cherish every moment. I would sing to her and talk to her, and she kicked. We went on hikes together, we went camping so that she could go camping with us, doing lots of those things. As Darren said, there are hard times, but I've realized that even the hard times were glorious in a sense because there was so much beauty coming through, and it's hard to necessarily predict that or see what glorious things will come through the hard times. But even the hardest moments were beautiful. We like talking about her. I think because we really do feel that it changed our lives for good, and we want people to know that.

Darren: Everyone's situation is going to be different. Everyone is going to go through something different than us, even if it's the same symptoms, if it's alobar holoprosencephaly or Trisomy 13, whatever it is. It's going to be a different thing, but it's going to be worth it. The best thing I think for us, is that we had family. Having our family around us and being able to have good neighbors and the support that we got was amazing.

Gerald: What advice would you give others facing a similar journey?

Sydney: If you want to carry that baby, then you carry that baby, and you hang out with people who will support you in that. My mom even threw me a baby shower and well, it was called, "Showering Sydney with Love," but then we found it all out and so people came, and they hugged me, and they made a scrapbook for me of things that were comforting to them. They gave me necklaces with a G on it or a little ring that she wore. People were on our side, they were on our team, and they wanted us to have the best experience we could with her, and they made sure that happened. So, we were very lucky that we had people who were on our side who knew that we wanted to carry her to term and who supported us in that.

Gerald: Tell me again your baby's diagnosis.

Sydney: It's huge, and I can even write it down for you if you'd like. It's alobar holoprosencephaly. Holoprosencephaly is where the brain doesn't separate, and some people can live full lives with it because there are different ranges. Alobar is the most severe, where there's no separation. I was able to talk to someone whose baby had lived six weeks, but that was even a long time. Talking to neonatologists, some live hours to days, if they even make it to birth.

Gerald: Thank you so much Sydney and Darren. Your story is inspirational to me, and I so appreciate your willingness to share with others.