An Orange Socks Story – Kristin and Chris: Trisomy 9

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was so glad to have the opportunity to meet with Kristin and Chris for an Orange Socks interview about their baby. Ethan had Trisomy 9, and he defied medical knowledge by being born alive. Kristin and Chris were encouraged multiple times to abort Ethan, but they chose to have Ethan, who lived 93 minutes. They are deeply religious people. Kristin's and Chris' faith has helped them put the life and death of Ethan into divine perspective. Although his life was very short, Ethan made a profound impact.

Gerald: I really appreciate your meeting with me. It's an honor to meet with you. Kristin, tell me, when did you find out your son had issues?

Kristin: When I was 20 weeks pregnant, we went in for our anatomy scan, and at the time, we just thought we were going to find out the gender. We knew they were gonna tell us more than whether our baby was a boy or girl, but that was what I was excited about and what I was really looking forward to finding out. We actually did not find out right away, and in hindsight, it makes sense to me that the technician left for a while and said, "Go ahead and get your husband now, and I'll let you guys know the sex of the baby." I went, and Chris came back in, and we probably sat there for 20 minutes. When she did come back, it was kind of rushed, "Oh, it's a boy. Look, there it is. Okay, great, you're done." At the time, we were just so excited that I didn't think anything weird of the fact that she disappeared for so long. That was on a Friday, and we got a call the following Monday from our doctor asking if we would come in as soon as possible to discuss the ultrasound. We were so worried because they wouldn't tell us why they needed to see us. Actually, they didn't even say we needed to discuss the ultrasound, they said we just need to meet with a geneticist. I was asking them, "Is this something everybody does, or is this just something that we've been chosen to do for some reason?" They said they really couldn't tell me much over the phone, that we really needed to come home. We were on a family reunion in Las Vegas which is about a three-hour drive from us. We ended up calling back and asking if they recommend our driving home, and they said yes. Then we were really freaking out because they wouldn't tell us anything over the phone. After driving back that night, the next morning the doctor sat us down and told us that they noticed a lot of abnormalities with our baby in the ultrasound. One of the things they noticed was that his brain was missing the cerebellar vermis, so the back of his brain just wasn't formed; it just wasn't there. They also noticed that his heart didn't look right. The geneticist couldn't quite pinpoint what was wrong with the heart, it just didn't look normal. They also noticed that he seemed to be growing a little slower than normal, so they wanted us to meet with a specialist to do another ultrasound so that they could see him in real time just in case the pictures weren't clear. The specialist met with us, looked at our baby again, and she was able to confirm that he did have some fluid built up in his brain, so he had hydrocephalous. He was missing part of his brain, and his heart didn't look normal, but she couldn't pinpoint what it was, so she said that we needed to see another specialist and have a cardiologist look at this closer. It all was a big shock. We just didn't have any idea that was, what we were walking into.

Gerald: But you didn't have a diagnosis at that point.

Kristin: We didn't at that point.

Gerald: Okay.

Kristin: Our diagnosis actually did not come until after our son was born. We were offered choices to find out ahead of time, and we saw a lot of specialists who kept telling us this doesn't look good. They had a feeling there was some sort of chromosomal abnormality, but they didn't know what was going on. They said we were probably looking at either severe mental and/or physical disabilities for the rest of his life or possibly death. They kept asking us if we were sure this is something we were ready for. I think that's a silly question, because I don't think you're ever ready for that, but we knew that we didn't want to take any chances with him because we knew we wanted him. They offered me the amniocentesis test which would take some of his cells. They would insert a needle through the uterus, take some of his cells and test those, but they kept warning me that the risks are really small, but it does raise the risk of potentially losing your baby or going into labor early. I was 20 weeks pregnant the first time they offered it to me, and they were offering it to me all the way up to 27 weeks or so. I had a lot of extra amniotic fluid, and I was sure that if they poked me, I would probably go into labor early. We kept asking if having a diagnosis now would make a difference in how they treat him, and all the doctors told us it wouldn't make a difference at this point, but it will help you know how to prepare. As much as we wanted to know, we figured we'd just wait until after he was born when they could do the same tests. We did the test after he was born, and it wasn't until after everything happened that they told us he had Trisomy 9, which comes in various forms. In the partial and mosaic version of it where it is not in all of the cells, some of those babies can survive, but with the full version, they rarely make it even to delivery, so he really defied a lot of odds even making it that far.

Gerald: Chris, what was going on in your mind when you got this initial diagnosis that your wife was carrying a baby who had some issues? What were you thinking?

Chris: At first I thought, this kind of makes sense, because I've gone through some different things in my own life before meeting Kristin, where different obstacles came up. This just seemed to be another thing, and it just seemed like this is what has been given to me so you need to figure it out now. The cool thing is that having a relationship with God has been a huge thing in all of it. Because even growing up, the relationship with Him has been what's gotten me through all those different obstacles. I found comfort in knowing that even though this is going on, God is with us in all of it. It was still scary because you're hearing different people telling you that with their baby, the doctors told them that things were looking not so good for the baby, but then the baby was born and didn't have any problems, so the doctors were wrong. So, you're thinking that side of it, that maybe the doctors don't know. That could happen, but maybe they are on to something, and if so, we will be okay with it. We will just have to figure it out. That was the initial thought process. I think I was little bit more calm than she was. She was crying a lot, and that's fine and natural. It wasn't until I started reading more about suffering in this life and the things that we go through while knowing that it's for a reason that started me crying as well, because it really brought it back full circle. Knowing how Jesus suffered on the cross and how our suffering isn't much compared to what He went through, but also knowing that He understands because He suffered and we suffered with Him. It's for a purpose, and there is joy in it, which sounds crazy, but there can be joy in suffering. I don't know if that answers your question.

Gerald: No, it does. I was just interested in what was going through your mind at the time. What type of advice were the physicians giving you? Often what I'm learning is that when there is something wrong, the physician will encourage termination of the pregnancy or will advise that way, or will strongly or not so strongly, depending on the physician. Did they approach you with that at all?

Kristin: I think every doctor we met with encouraged us at one point or another to terminate our son. We had one doctor who was the main specialist that we met with fairly regularly throughout the pregnancy, and she only offered it a few times at the first appointment, but I believe she caught on pretty quickly that that wasn't something we were interested in. Given Ethan's condition, we did meet with multiple specialists, and every single time we met somebody new, that was one of the first things they offered. They often times would ask if we were sure we were ready for this, that "This is going to be a lot on you. You're a young couple and you have your whole life ahead of you, are you sure you're equipped and ready to have a child who may have special needs or may have a lot of physical needs or who that may have poor health?" It seemed like a weird question, because I don't believe that anybody is ever ready. I don't think you can prepare yourself for something like that. We knew that we wanted him even though it was scary, but everybody continually offered that to us over and over.

Gerald: You obviously had the baby, and you need to know that probably this is not the first time you've heard this, but you named him Ethan, and he is the first person I've ever heard of with Trisomy 9 who lived through a delivery and was born alive.

Kristin: If you don't mind me adding to that, even the doctor delivering Ethan told us that same thing after Ethan was born. We sat down with the doctor and the geneticist, and I believe somebody else, and they were going to talk to us about the results of the testing that we had done on him.

Chris: That person was a care person that the hospital provides.

Gerald: Like a social worker.

Chris: Like a social worker.

Kristin: There were a few people in there, and I remember the doctor was in there, too. The NICU doctor was in there who cared for him. We were asking a lot of questions. “What are the odds of this happening again? Is this something that we can potentially carry? How common is it that you’ve seen this?” I remember she just looked at us and said, “I’ve never in all my years seen a baby born with Trisomy 9, ever.” Which is amazing that even in the medical field, and someone who had worked in a hospital for years delivering babies every single day, she had never heard of a baby being born alive with Trisomy 9. A lot of our doctors told us that this baby should have miscarried really early on, and they kept using the words “should have,” which seemed ironic, because he did it, he fought until the end. Part of everyone’s argument for encouraging us to terminate was that these babies don’t make it far. “He’s not going to survive. These babies are usually miscarried within the first few weeks before you even know you’re pregnant. It’s a miracle you’re even this far. You’d be doing everybody a favor just to end it now.” It’s amazing how rare it is, and it makes you feel even more alone, but it is incredible, too, that he really was a miracle despite all of the challenges that came with it.

Gerald: So, he was delivered.

Chris: Yes.

Gerald: Chris, what were your thoughts when this little baby came into the world?

Chris: It happened so fast, because when her water broke and we went to the hospital, we knew she was in labor. When we got there, they had a talk with her, trying to keep him in as long as they could to get us to Kyser Sunset for the delivery. But the next morning, on Sunday morning, they realized that he was breach, so they said, “You’re going to have this baby now,” and they had scrubs for me to put on. They said that they were going to perform an emergency C-section on her, and I think we looked at each other a couple of times, but I don’t know if we said anything to each other.

Kristin: It all happened so fast.

Chris: I remember putting the scrubs on, and she got wheeled out to the room where they were going to prepare her. They told me to wait a little bit, and it wasn’t that long before I was able to go into that room with her. They had kind of a curtain in front of her to perform the C-section, and right then we prayed together, and as soon as we were done, they had gotten him out. It seemed really fast, and I was thinking that it was going to take longer. They said, “It’s a girl,” and we looked at each other like, “What?” Then, “Oh, no, it’s a boy.” It was kind of humorous at that moment. Then he was so small, and they brought him over to the incubator. I asked if that was our baby because I was just in shock that it was so fast. They brought him over and were performing percussions on him and giving him oxygen. I got up to go over there, and they asked, “Yeah, dad, do you want to hold him?” I said, “Yeah.” So, I went to go get some gloves on from the wall, and they said that I didn’t need the gloves because he’s yours.

Kristin: Because they all had gloves on.

Chris: I just thought I needed gloves, too. I put my finger in his hand, and he held it while they kept working on him. It was cool to be able to be there initially with him when she was there, but she couldn't be right there. Then it was really sad after they said that there is nothing to do to keep him alive, so they allowed us to spend some time with him. She got to hold him on her chest, and then our other family members came in and spent some time with him, too. It was definitely a different experience than what you would normally see, I guess.

Gerald: What were your thoughts at this time? He was born alive, and he was alive for a period of time. How long did he live?

Kristin: He lived for 93 minutes.

Gerald: 93 minutes. What were your thoughts during that time? Obviously, they were working with him.

Kristin: The whole time they were working on him, I was relieved that he was finally here. I was also terrified, and I kept asking Chris, "Can you see him? Is he responding? Is he moving? What is he doing?" He didn't cry because I think he was just really weak when he was born, but Chris was over there with him, and it made me feel so much more peace and relief knowing that his dad was with him. Chris was holding his hand, and I could hear Chris talking to him, but I was really, really scared and didn't know what to expect. I was just praying that our baby wouldn't die. Then the doctor came up to me at one point and told me, "I'm really sorry, but there is nothing that we can do." She walked away, and she said it so calmly that after she left, I didn't know If I could comprehend what she just said because she was just so straight-faced when she said, "I'm sorry, there is nothing more that we can do," and then turned around and walked away. In my mind, I thought, "Wait, does that mean he is already gone? Does that mean they are going to stop working on him? What does this mean?" Everything just felt so foggy in the midst of just having had this baby and the rush of laboring him this quick. "We are going to transfer you to Kiser in LA. Oh, never mind, he's here and we need to get him out now." It was just a lot of fear in that moment, but the moment they handed him to me, I remember people telling me the whole time I was pregnant, even before I was pregnant, every pregnant mom would say, "The first time you see that baby, you're going to forget all that pain that you went through in labor. You're going to forget all of that. It's going to all fade away the moment you look upon that baby's face." I really found that to be true. It wasn't just the physical pain of having labored him, it was also all the emotional pain and all of the mental pain and just all of the different types of pain that we had gone through in the weeks leading up to his birth. It was like I forgot about it all the first time I saw him, because he was just perfect, even with all of his imperfections in the eyes of the medical staff and the little anomalies that the nurse pointed out to me later. You don't see all that when they hand you your baby, you just see this perfect little thing who has his dad's hair and my nose and all those little things that you just see when you look at him. As much as the moments leading up to his birth and right after he was born were filled with so much fear, it all just went away the moment I saw him.

Gerald: What kind of effect has that little life had on you two and on your immediate families? I assume that some of your folks were there and were able to come in and hold him, too, and see him at any rate. What kind of effect did he have? You can go first, Chris.

Chris: It brought some family members, who weren't as close, closer together to us. As an example, I had a cousin around the same time who is currently alive today, and they were told that he didn't have any problems going through the pregnancy, and then he was born with a few different health complications. We've gotten to talk to her and her husband and been able to relate on that level. As far as Ethan himself, it was really amazing to see how when we had a service for him, we invited anyone who wanted to come. It was at our church, and there were a ton of people there, it was incredible. It made me think, "Man, I hope that I can leave the type of legacy that he left and the type of impact that he left," because there were just so many people there. Coworkers, family, friends, people that we wouldn't have even thought to have shown up, showed up. We were thankful that through his life and his death, we were able to share his story with those people.

Kristin: Yeah.

Chris: Do you have anything to add to that?

Kristin: I think you hit the nail on the head when you said that looking out at the crowd at his memorial service, we just kept saying that if a half or a quarter of this many people come to my memorial or my funeral one day, that would be considered that I really left an impact, or people were really touched by my life. I think we had nearly 400 people there. Chris has mentioned a few times that our faith is really important to us, and we've had so many people ask us questions about our faith because of our story. People have asked us a lot of different questions about life and suffering. A few other things that I've been able to do is write a lot, and I blog, and I've had so many people reach out to me who have either lost babies, or are in similar situations. I have a handful of people who I now consider my close friends. I've walked through their pregnancies with them. Even if it's through Skype or video chat. Thanks to technology, you can have friends in Texas and Illinois and Indiana and all over the US who have maybe had a completely different diagnosis, but they've had a child with a diagnosis that was really scary at the time. There are friendships have come out of it. Last fall, I had the opportunity to speak at a parents' workshop for people who have lost young children, and I got to be a part of helping plan it and then speaking at it. It was in the Midwest, and I got to go out there and just love on these families who had been through similar things as us. It's not like we have all the answers or anything. This just fell into our lap, but having someone sit with you and walk with you who gets it, even if they don't get every single detail, they will understand some of it, and that is so powerful. It has been an honor to be able to walk through this with some of the families that we've met. I just think of the friendships we've made, and I think of the people who have come to me when they've been at different stages of their pregnancies and have asked questions, and I think how many lives Ethan has touched and the lives Ethan has saved, and it’s really incredible. I think about him all the time, and we often say that we are proud parents. Even though he is not here, I’m so proud of him. I feel like a proud momma over just the ways that he has touched peoples’ lives even in the short 93 minutes that he was here.

Gerald: Let me ask you this as a final question. You had a scary pregnancy. Fairly early on, you knew something was wrong, something was amiss. Every doctor that you saw was mentioning termination of the pregnancy for various reasons. You went through an entire pregnancy. You had the baby, and the baby lived 93 minutes. Was it worth it?

Kristin: Absolutely.

Gerald: Was it worth it, Chris?

Chris: Yes, absolutely.

Gerald: You guys are awesome, thank you.

Kristin: Thank you.