An Orange Socks Story – Lacey: Syntelencephaly

Interview by: Gerald Nebeker, President of Orange Socks

Today I have the honor of speaking with Lacey and having an Orange Socks interview about her son, Tell, who has syntelencephaly and partial agenesis of the corpus callosum. Did I get that right?

Lacey: That's right.

Gerald: Okay, awesome. Thank you for meeting with me, it's an honor.

Lacey: Sure.

Gerald: Tell me a little bit about when you first found out that Tell had some issues.

Lacey: I was pregnant with twins, and at 20 weeks, they noticed Baby B, who was actually Tell's brother, had a heart problem undetected. They just wanted to look into it basically, so they said I needed to go see a specialist perinatologist and have some in-depth ultrasounds. At 28 weeks, I scheduled it, and my husband was in a meeting and couldn't come. I just went, thinking that, "They're just going to double-check his heart and that everything is going to be okay." I get in there, and they said, "Baby B looks great, but where is your husband?" I said that he couldn't make it today, and they said, "Oh well, Baby B looks good, but there is a problem with Baby A," and you never want to hear that.

Gerald: Right.

Lacey: I was crushed, of course. That's when they told us something was going on with his brain, and they didn't really know what to tell us at the time. From then on, we had ultrasounds weekly and an MRI, so from 28 weeks on, there was a lot of worry and questions and Googling different diagnoses because they wouldn't really know until he was here.

Gerald: Right.

Lacey: Every week it seemed like I would go in and they would tell me something else was wrong or something was worse, or he wasn't going to make it to birth, or he wasn't going to make it after birth, or he would only make it to age one, or all of these awful things. And I just remember coming home and calling my mom. She lives about an hour and half away, and she made the drive in an hour. I remember just feeling crushed and feeling like all the hopes and dreams that you have for having these two little boys who bring so much joy and love, those expectations are totally different now. And you wonder if you can handle what you've been given, I guess.

Gerald: When did they actually come up with a definitive diagnosis?

Lacey: Right after he was born. They were both in the NICU, and they did an MRI, which was kind of scary. He quit breathing after they did it, but I think it was because of his ventricles. It knocked him out more than it should have. After the MRI, they had the neurologist come, and that's when they decided that's what he had, and it's not very common.

Gerald: About how many people have this?

Lacey: Not very many. I did a lot of research, and I love that you guys are doing this because, I just Googled syntelencephaly wanting so badly to know someone else who has been through this diagnosis or knows anything about it, and I was able to find two similar situations. They are not exactly like Tell, because the diagnosis is so broad, so I've only found two.

Gerald: So, you brought him into this world not really knowing what you had. The doctors had made several different guesses about diagnoses, which were wrong apparently, it sounds like.

Lacey: Yep, they were.

Gerald: I'm glad Baby B didn't end up with heart issues.

Lacey: It was quite strange. After my babies were born, I had been so worried about the whole pregnancy and about Tell, and he was the one that I got to hold afterwards. They took the other one off to the NICU, but I got Tell. Then they said, "We want to talk about his diagnosis, we want to do this," and I said, "It doesn't matter anymore. He's here, he's breathing, he's fine. We'll do what we need to do to get him where he needs to be," and it didn't matter after that.

Gerald: What have been some of the hard things about having Tell, and some of the challenges that you faced so far?

Lacey: It's hard when they don't meet milestones. I think it's a little bit different having two of them at the same age and one with special needs. I feel like my other kids miss out on a lot, but he's also brought so much joy that it's hard to say that there's been anything negative. It's hard because he looks so normal. I feel like I need to explain all the time about him, and I don't want to have to do that about my child. I want him just to be him, and so that's been hard. It has been hard trying to figure out how to help him through his social issues or his sensory issues or things like that, but it has also been amazing to learn.

Gerald: Describe some of the issues that someone with this diagnosis has since it's rare.

Lacey: It is.

Gerald: Some of the listeners may have never heard of it, like me, and would like to know what in the heck is that?

Lacy: I saw on your site that there is anencephaly.

Gerald: Right.

Lacey: There is a big wide range of holoprocencephaly and syntelencephaly, all these different ones. Tell's is more on the mild spectrum of that. They told us things that we could expect are seizures, learning disabilities, problems with muscles, delay, and just different things like that. Once again, they don't really know, so they tell us to watch for these things, and who knows if they'll happen, or if he'll do it. They do this baby watch, and a lady would come into my home every month and look at the twins and see that they are doing this, so that's good. They follow them for a year just to make sure they are on track, and at about six months old, Tell wasn't keeping up with his brother Ren. My biggest concern is that I want him to have the best life that he can have, and if I could do something to help him, I wanted to help him. We started having early intervention come in, and we helped him roll and sit up, kneel and stand, just things we take for granted in "normal" kids. We worked so hard for him to be able to do those little things, and those victories were so sweet, like when he started walking after they told us he would never walk. It's hard to say what to expect.

Gerald: Tell me about the joys.

Lacey: It has been amazing and one of the best blessings in my life. We have three older children, and we found out we were having twins because I wanted one more, and that was a little bit crazy, but I'd been through a lot in those six years and always just wanted one more, so to get two was huge, like so much fun. Their little relationship is amazing, you can definitely tell that his brother watches out for him. He introduces him to people and protects him. That's not to say they don't fight, because they do, but it has been amazing to watch him learn and grow. It has also been amazing to watch my older kids have a little brother who has some special needs who isn't like everybody else. It makes them more aware of kids around them. They stop and think maybe they are doing that for a different reason, maybe I shouldn't be so hard on them, maybe there's something more that I can't see. That to me has been amazing, just the love and the family support. He is my dad's favorite, not that he doesn't love his other grandkids, but there's just something special about him. There's just a sweet spirit about him. I always worried when I was pregnant if it was going to be hard and if I would be able to handle it, but those are the things you don't realize when it's the "What if? What's going to happen? What's that going to be?" You don't get to see that part. I wish I could go back and tell myself that it's going to be okay, it's going to be hard, but it's going to be okay, and you're going to have so much joy and so much love in your heart for this little boy that it'll be okay.

Gerald: You mentioned your father. What other impact has he had on your extended family or your immediate family? Who else has been impacted by his life?

Lacey: I felt so broken afterwards when I got that diagnosis and so crushed, and I felt, not really hopeless, but you have to mourn the loss of what you thought was going to be, so I turned to my older brother. I remember that day going to his gym and him just hugging me and crying, and now he is his biggest cheerleader. He is always looking out for him. The neighbors in the ward love him. He's just an amazing little boy, and I think he's impacted many different lives. He has just brought so much joy to us that I don't know what we'd do without him.

Gerald: If I came to you just receiving a similar diagnosis that my wife was going to have a child with exactly what your son has, and I'll pronounce it again syntelencephaly, what advice would you give me?

Lacey: One, not to Google. Two, you never know how it's going to work out. You have all these big fears, but there's also faith that you have to have. I think you have to have faith that even if it's going to be hard, it's going to work out. It may not be what you thought it was going to be, but you could learn so much more from these special little kids who are housed in these imperfect bodies. It has been amazing to see his spirit grow, he has been amazing for us.

Gerald: That's great. Any last words that you want to tell the world?

Lacey: I'm just so grateful that you guys are doing this. Being a mother with a scary diagnosis and having nowhere to turn, it's a dark, scary place, and I'm so grateful that you're doing this just to make these diagnoses be more real, more personable, more "This is what they were diagnosed with and it might not be the same, but this is similar," because that gave me so much hope when I found someone else similar who knew what I was going through, how my heart was breaking, how I was being overjoyed. It's just nice that you guys are doing this.

Gerald: Well, thank you, you're awesome. I appreciate your taking the time to talk about Tell and his impact on your family, so thank you very much.

Lacey: You're welcome.