

## An Orange Socks Story – Lacey: Tessier Cleft

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was thrilled to have an Orange Socks interview with Lacey about her son, Christian, who has a very rare condition called Tessier cleft, or frontonasal dysplasia. Lacey figures there are about 50 people in the world with this condition to the degree of her son's. In addition to family responsibilities that include being a busy mom with two children, Lacey is an attorney and book author. I am confident you will enjoy hearing Lacey's story.

Gerald: Lacey, thank you so very much for taking the time to meet with me for an Orange Socks interview to talk about your son, Christian. When did you find out that he had Tessier cleft, sometimes known as frontonasal dysplasia? When did you find out that he had that diagnosis?

Lacey: Thank you for having me. We actually found out about Christian's diagnosis in utero. We went in for our anatomy scan, mostly concerned with finding out whether he was a boy or girl because we were ready to start shopping. We never imagined in our wildest dreams that there was going to be anything wrong. We went in for the ultrasound, and everything was fine that day, but later that week, they called and told us that they had seen something on the ultrasound and were concerned, and needed us to come back. From there, it progressed throughout the pregnancy trying figure out what was really wrong with him.

Gerald: With that concern, did you get any advice from the docs who were working with you on what to do?

Lacey: This birth defect is really rare, so we didn't really get a specific diagnosis until after he was born. Throughout the pregnancy, we were hearing things like, "They found this today on the ultrasound, but now it looks like this is going on." Then we'd come back in a few weeks and they'd say that, "Now it looks like this." They just never could really get a clear picture of what was going on. On top of that, his having a really rare condition didn't make it easier for them to name something without actually being able to see him, so what we were getting was more of we were just going to have to wait and see, every week was a wait and see game.

Gerald: Interesting. How old is he now?

Lacey: He turned six in February.

Gerald: Okay, so what have been some of the challenges that you've had with Christian for the last six years?

Lacey: We have the medical challenges. He's had to have several reconstructive surgeries, and we've had to deal with things like chronic rhinitis because he always has an over-production of mucus, like a cold that's hard to get rid of. They've not been fun all the time, and they've not always been easy, but I think the biggest challenge that we've had to face is social stigmas.

Christian looks radically different from what most people look like, and we don't care, we think Christian is beautiful, and he is beautiful. We love Christian for who he is, and his condition and his appearance are not even on the chart of things we consider on a daily basis about him for his value or his worth. Unfortunately, that is not how the rest of the world sees it, and we have had to push back on a lot of social stigmas about people with disabilities and people who have facial differences. We've had to deal with a lot of nasty comments about our own child, about a child with a condition, and that's been the hardest part, because we know his value and we know his worth. It's hard when other people can't see that because they can't get past his facial difference.

Gerald: He had a cleft lip and cleft palate, he is also blind, is that correct?

Lacey: Yes, the simplest way to put it is that his eyes also clefted along with his cleft lip and palate.

Gerald: So how is he physically, health-wise?

Lacey: What you see is what you get. His appearance is the extent of his condition, so other than having to deal with things like his vision impairment and stuff like that, he's a very healthy, typical six-year-old child.

Gerald: What have been some of the joys you've experienced with having Christian in your life?

Lacey: There have been so many joys with Christian, he is just one big ball of joy really. I always say in this family, joy is a lifestyle. We don't spend time fretting over his disability, and we don't spend time worrying about what we are going to do tomorrow because Christian's blind. He's going to grow up one day and still be blind. We don't worry about that every single day that we get to enjoy Christian and hear his laughter and watch him just enjoy life. It brings us joy as a parent, seeing your child happy makes you happy, and Christian is happy all the time about everything. He loves the same types of things that any typical six-year-old loves. We get to enjoy raising a six-year-old little boy, and the thought that he could have not survived after birth makes us all the more grateful because we can see all the things that we might have missed out on had he not survived. We're just thankful that he's here. We're thankful that he is healthy despite his challenges. We have so much joy that the challenges don't mean a whole lot when the alternative was not having Christian at all.

Gerald: That's wonderful. What impact has his life had on your family in general, your extended family or your immediate family? You have a younger sibling, do you want to talk about that a little bit?

Lacey: I think the biggest impact Christian has had on our family is giving us perspective. There are not a lot of things that can get you upset and bother you when you've just spent five days in the hospital getting your child better from surgery and then they are better and now they are healing, and the surgery helped, so if this thing didn't go the way we planned, let's keep

moving. The little things are little things, they are just not significant. Along that line, we know that the big things are big things. We really have the perspective of what's important in life, and I think Christian has given that to us. We get to see the beauty in every day, and getting to be Christian's parents, whatever challenges we have to face, that's worth it; that's the perspective that he's given us.

Gerald: His life also inspired you to write a book, *Through the Eyes of Hope*, which I just bought on Amazon by the way.

Lacey: Oh, well, thank you.

Gerald: So why did you write the book?

Lacey: Well, the short answer is that I love Christian so much that I wrote a book about it. But the longer answer is that I have spent pretty much all of Christian's life pushing back against that stigma I mentioned earlier, and I feel like if there's only one side of the issue being presented, then that's all people are going to hear. I wanted to present the other side of the coin, kind of like what Orange Socks is doing. I wanted people to see the joy, because people would look at Christian when we'd be out in public, and you could just see the overwhelming sense of pity on their faces, or the overwhelming sense of shock on their faces. I would think, "C'mon ya'll, we don't want pity. There is nothing to be surprised about. We're happy and we're joyful." We think people look at Christian and automatically think that must be so hard, those poor people, and that's not the conversation we want people to be having, and that's not the world we want Christian to grow up in. The book was just one way for me to get our story out there and let people know that there is so much good and there is so much to be found in the life that we didn't plan.

Gerald: That's awesome.

Lacey: Yeah.

Gerald: Let me ask you, if I just found out either in utero or thereafter that I had a child with a similar diagnosis, what advice would you give me?

Lacey: When people ask me this, I always think of that poem, "Welcome to Holland," and I bet you've read it. I remember reading it for the first time and the impact that it had on me. I think it sums it up perfectly that it's not a journey that we ever would have chosen, it's not a destination that we would have picked, but there is so much wonder and beauty in it, that when babies are in utero, that's sort of what we experience. There's so much uncertainty that it's terrifying and scary, but it will be worth it. It will be more beautiful than you ever would have imagined, and that child will teach you. We as parents think we will teach our children, but that child will teach you so much about life and so much about who you are and who you want to be. It's a wonderful journey, and I feel like sometimes God knows what He's doing

better than we do. We think we know what we want or what we need, and sometimes we don't get what we need.

Gerald: Yeah, well, that's great. Awesome. I think it's wonderful that you wrote the book and that you're so out there with your son.

Lacey: Thank you.

Gerald: I see picture of him, and he's awesome.

Lacey: Thank you.

Gerald: Any final remarks that you'd want to give?

Lacey: I think we've covered everything pretty well.

Gerald: Thank you so much for taking the time to talk with me.

Lacey: My pleasure.