An Orange Socks story- Jessica: Pierre Robin Sequence

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was happy to have the chance for an Orange Socks interview with Jessica, whose daughter, Eliana, was born with Pierre Robin Sequence. Although often diagnosed in utero, Eliana's condition was a surprise to Jessica and her husband.

Gerald: Jessica, when did you find out that your daughter had some issues?

Jessica: When she was born was when we found out. She was breach, so I had to have a C-section. We had a scheduled C-section, and in the OR they took her out and brought her over to the table and started inspecting her. At that point, my husband left my side and went over to her as they were checking her out. Being the anxious dad he is, he asked if everything was okay, and the nurse answered, "Yep, everything is doing good." As soon as she started feeling around the mouth, she said, "Oh," and he asked, "What's wrong?" She said that she has a cleft palate, and as they are doing this, they are still checking her out. One of the nurses came over to me because I was still on the operating table, and she said, "I just want to let you know that she is looking good, but she does have a cleft palate." I was trying not to be emotional and trying to be reserved, so I said, "Okay," and finally they finished her up and brought her over to me and laid her on my chest, as I was still on the operating table. I looked at her and thought she looked completely normal because when I heard cleft palate, my first thought was cleft lip. I looked at her and said, "There's no cleft lip." We found out that she had the cleft palate, and the first day or two, that's kind of all we were told. They took her to the NICU, and they were watching her there. They said they just wanted to watch her, and at some point, they started mentioning that she has a recessed chin, too. They wanted to watch that, so we were okay with that, but that seemed like a minor thing, because their attitude was, "Oh, she has a cleft palate, and that's the issue, this recessed chin is just like a freckle." Then it was probably around day three that we learned more of what was going on. She had a recessed chin, and that was the main reason why they were keeping her in the NICU, because your tongue is connected to your bottom jaw, and because her chin was way far back, so was her tongue, and her tongue was falling back and blocking her airway. That was her major issue, blocking her airway and essentially choking on her own tongue. It wasn't safe for us to have her outside the NICU. She was born on Wednesday, and by that Sunday, she was transferred by ambulance to another hospital that could better take care of the diagnosis. I think the first time we heard Pierre Robin was when we got to that hospital. At the first hospital, I think they knew what was going on, but they knew that the resources at that hospital were such that they couldn't do anything, hence the transfer. That's when the doctor started talking to us about the Pierre Robin, and what she eventually had was mandibular distraction. At that hospital, they have a protocol for kids who qualify for Pierre Robin but also quality for mandibular distraction because there are different things that you can do for these kids. Some you can just position always on their side or their stomach, and they breathe well. They did a sleep study on her for general observations and decided that what she needed was surgery. At two weeks old, she had a mandibular distraction where they actually broke her jaw and put in distractors that help move the jaw forward in tiny, tiny movements. She had these little screws that would stick out behind her ears, and twice a day at 7am and 7pm, they would turn them just a tiny bit, which would move her jaw a tiny bit forward. Because she was a baby and their bones grow so fast, new bone growth just happened. It took them about a month, but they moved her jaw forward to the point where her tongue wasn't falling back. I remember, probably when I was feeding her, for the first time I saw her tongue past her gum line, and I was just shocked. Before it was just so far back there, it would only be if she was crying and have her mouth wide open that you could see her tongue.

Gerald: What were your thoughts when you found out that your daughter had this issue? What were you thinking? Has anybody in your family had this issue?

Jessica: No, it can be genetic, but our case was isolated so it was just completely random. They don't really understand why it happens as it does. They understand why she had the cleft palate though. As she was growing around 12 weeks in utero, her chin didn't come out far enough, so her tongue was up on the roof of her mouth and as her palate was forming, that hole stayed there. It's actually a U-shaped cleft where a lot of kids with cleft lip or cleft palate will actually have a V-shaped hole. Hers is a U, just like her tongue, because that's what got stuck up there so it didn't form. A lot of times you'll hear it referred to as Pierre Robin Sequence, because it is a sequence of events. Your chin doesn't go forward, so then you get the cleft palate. When we first found out, I think there was just kind of this shock and disbelief, then realizing that you're going to have to plan for this NICU stay that was never in your original plan. Then it was also trying to figure out how we were going to handle this. We had a two-and-a-half-year-old who needed attention who just couldn't hang out in the NICU all day and who really didn't like hanging out with other people besides myself. I remember talking to my husband who said he didn't know what to do. I said, "Well, before she was born, before we knew there was any issue, all our friends and our families said they were here for us, so we just need to start calling people and asking for help." This is when our church was great, somebody from our church was able to come be our babysitter with our daughter. She would go to the hospital with us so our daughter could still kind of be with me, but then they could go off and explore the hospital as well. It was a children's hospital, so there were playrooms and stuff for them to do. They also brought us food, so basically for three months, I didn't cook anything. I don't know what my initial thoughts were. I remember going back and kind of reflecting on the name we gave our daughter, which was Eliana Mercy. I thought both of those names kind of fit her. Eliana means that the Lord will provide, and He really has through her birth, and I thought Mercy is kind of what He gave us through this whole situation. I know, too, that there were some thoughts worrying about her future and what it's going to be like. When I was still in the hospital recovering, I worried about her getting older and dating, and was she going to find a spouse who is going to love you despite this. You start looking at trying to find other people who are in this same situation, and what do they look like. My sister was really helpful, giving me reassurances that your facial appearance isn't the only reason somebody would love you. I think you worry about that stuff, and you worry about when she is in grade school, what will other kids say. At this point, her facial features look normal, but there's still a long road ahead. We know that she is going to have to have cleft palate surgery, so we have that one marked in our minds, but sometimes as kids like her get older, their chin doesn't grow at the same rate as the rest of the facial features, so sometimes they have to have another mandibular distraction. When she had it at two weeks, she was a baby who slept most of the time anyway and didn't know what was going on. Then I think, am I going to have to go through that process with my nine-year-old who is going to understand and remember the pain that she is going through? There are still some of those worries. There's also just the reassurance that I know God will provide. I know that He gave her to us for a specific reason, it wasn't coincidence that she was brought into our family or that she was even born with this diagnosis. I just think that you know through this, there have been seeds that have been planted her life that will make a difference, and she's being shaped into the person that she's going to become. Part of her diagnosis is that she is going to be different having gone down this road. I even think with my older daughter, even though she's only two-and-a-half, that this is shaping her, too, because doctor visits are becoming something that are commonplace. It's actually, she loves going to the doctor's office. We talk about the different types of doctors, "Oh, this is the ear doctor, and this is the eye doctor." She'll ask me questions, so in a way, it's shaping her even though she was not the one diagnosed. It's shaping her to become this different person. There's no way to know how they would be different without this diagnosis, but I know that it's shaping them into better people who focus on others.

Gerald: You kind of answered a question I was going to ask, which was what impact has her life had on others around her, like your family as well as your extended family? Is there anything in terms of your parents, or your husband's parents as to how she has affected them?

Jessica: I don't think she has affected them any differently than a normal granddaughter would. They love her and gush over her. There are more prayers they probably have for her than the typical baby, but their reaction to her is just like any other reaction that a grandparent has for their grandchild. In our bigger circle, our church has really rallied around us. We constantly kept them updated with the stuff that is going on, and even though I don't know the full extent, I think our walk through this as a family has impacted other families, giving them this different perspective. When you're pregnant and you have a baby, you expect that everything is going to be normal and perfect and just this sweet story, so to see it not be this sweet, easy story, but to see that everything still worked out okay, I think has impacted people. At this point, she is only six-and-a-half-months old, and I just know that her story and her experience will impact even more people as she continues to grow and as our story grows as well.

Gerald: So now if I came to you with the news that I had a child with a similar diagnosis, what advice would you give me? I'm now brand-new to this, maybe I find out in utero, maybe not. Maybe it's something post, but I'm confused, or whatever I am, so what would you tell me?

Jessica: Take one day at a time. When you start trying to worry too far ahead, you just get yourself in a worry rut, because you can't worry about the future. I remember when she was still in the NICU and I was worrying about her cleft palate surgery that was 12 months away. You just can't worry about the future as much, you just have to take one day at a time and one diagnosis at a time. As a new parent, with any diagnosis, start recording everything, so when you go to a doctor's office, write down who you visited and what was said. Start a binder with all of their paperwork in it, keeping track of everything, because every new person and every new doctor is going to want to know specifically dates and who said what. That was something our pastor's wife said. They adopted a boy that had a cleft palate and cleft lip, and she told me pretty early on to start a binder, and that has really been invaluable advice. At every doctor's appointment, they ask me a question and then they are so happy that I have a binder, so the doctors appreciate it too.

Gerald: That's great. Any last words that you might want to offer to people who are going to listen to your story?

Jessica: It's really hard seeing your child go through surgery. She's had two surgeries, because she had the mandibular distraction surgery where they moved her jaw forward, and then she had a second surgery when she was five months old to actually move the distracters. There are metal bars there, and it's really hard seeing your child go through surgery and knowing that we have to go through this again with the cleft palate. You just love on them, and you're there for them, and I think at the end of the day, when children know that they are loved and are being cared for, that's the most important thing. You hold them when the nights are rough and they are crying because they are in pain, and you're just there for them. Whatever happens, you just bear as much of the burden as you can, and you be strong for them, push through it, and reach out and get support when you need it.

Gerald: That's great, I appreciate it.