An Orange Socks Story-Leslie: Achondroplasia

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was very excited to have an Orange Socks interview with Leslie about her daughter, Lilah, who has achondroplasia, a type of dwarfism. They did have indications that Lilah had issues at a prenatal checkup, and experienced all of the questions and fears associated with the unknown. I was especially grateful for Leslie's honesty in talking about adjusting to their new reality, a path very similar to my own.

Gerald: Okay, so Leslie, thank you for taking the time to meet with me. I'm honored to have this chance. when did you first find out that your daughter had achondroplasia?

Leslie: Well, let me give you a little backstory about my son, and that will explain a little bit about why we were so surprised with her diagnosis. So, when we were, gosh, 30 weeks pregnant, they were telling me that he was going to be really small. And he was measuring really small, they did lots of testing and that kind of thing. And they were worried that I had something called IUGR, intrauterine growth restriction, and so at that time they were considering taking him early because they didn't think that he was growing inside anymore. And so, they thought he would be better off if they brought him out into the world and he would be in the NICU. And so, we did stress tests twice a week for the last 10 weeks of my pregnancy. They did take him a little bit early, and when he was born they said, "Oh, we were wrong." He was perfectly fine and healthy. And so, when I was pregnant with my daughter, they started telling me the same thing around the same time, "She's looking small, your measurements are a little off, you're measuring small, we want to do some stress tests, and some more ultrasounds," and so forth. And I literally just blew it off because I said, "Oh, you're wrong, you know, I just have small babies. Everything is fine." And so, I did go in for an ultrasound, the doctor said, "The measurements are looking a little small, we want you to go and see another ultrasound tech." In the meantime, we had switched doctors and moved locations. So, we went to my new doctor, so we did the ultrasound and the ultrasound tech took a very long time. Looking back, in hindsight of course, I realized she knew right away that something was wrong. But I, at the time, was just really annoyed because my two-year-old was running around, and she was taking a really long time. And so, after that the doctor put me in a room with my two-year-old, and came in five minutes later. He walked in, grabbed a seat, put a tissue box under my nose, and pulled up really close to my face and just looked me in the eyes and said, "Leslie, I think your daughter is going to be born with dwarfism." And, of course, just knowing my background with my son, I tried to talk him out of it, and tell him that he was wrong and that I just had little babies and that and nothing was wrong. He stopped me mid-sentence and said, "I'm 99% sure." And at that time, I really trusted this doctor, and so I believed him. And looking back, achondroplasia especially, it's hard to diagnose in utero and he was just guessing. The only way to confirm the results, was to do an amnio and at that time I wasn't willing to do that. And so, we just went with the assumption that he was correct, but we wouldn't find out until she was born at 40 weeks. So, when I heard the news, of course it was just me and my son, so I tried to call my husband. And of course, it's like the only time he didn't pick up the phone. So, I called him back, and I called him back right away, and he finally picked up the phone. And it was the first time that I had ever in my life said dwarfism, and all the sudden I became the bearer of the bad news, and it felt so surreal coming out of my mouth. It felt like someone had stamped my forehead, that wasn't mine and it didn't belong to me, but yet it was attached to me. And I knew that it would be attached to me forever. I was really afraid because I just didn't know much about it. It was a huge unknown for me, and fear of the unknown, you know, there's always questions and you worry about what you don't know. And so, the biggest emotion I had right away was just fear. I was really scared, it was really just a dark day for us, we cried a lot. We were really emotional, and just frightened for our daughter. The first questions we had, "What will her life span be? What will her quality of life be?" And then one question that we had to ask, that we didn't necessarily want to hear the answer to, "Will she survive the birth, and what are her chances of survival?" And what I didn't know at the time is that there are several forms of lethal dwarfism. There are 200 forms of dwarfism overall, but there are several forms of lethal dwarfism. And that in those cases, the lungs don't develop enough to be compatible with life. And I didn't know that going into that, but I did know that what if she didn't survive, and I had to wrap my head around the possibility that I wouldn't have a daughter moving forward. That was the scariest part for me, rightfully so, if looking back they had been wrong about that type of dwarfism. It could have easily been a different story, and a different situation, and we would've had a different ending to our happy ending, it wouldn't have been the case. But yeah, that is how we found out, how we felt about the diagnosis at the time.

Gerald: And it was confirmed when she was born?

Leslie: When she was born, we took lots of precautions just in case there were complications with her birth. Her birth story is one of the most incredible stories I've ever heard. We had a C-section, so it was so odd going into the day knowing we were going to have this baby. It was the first snowfall of the year, so we woke up to all of this snow, and it was just like everyone's blessing being poured down on us. It was so surreal, and we went in, everything was routine. And then we were aware that her birth weight would be a good indication of just how she was doing overall. And so, we were really nervous, but when she was born, we were waiting to hear, you know, "Is she breathing? What's her birth weight? Is she okay? Is it achondroplasia? Is it different?" You know, we just wanted to hear good news. And we did, we heard amazing news. When she was born, I heard her cry right away, and I sighed a little bit of relief knowing that there's air in there, she is breathing. And then the next thing I saw was a team of doctors, there was so many people in the room. And they all just crowded around her, and they were working on her, and I just was praying, "Please let her be okay, please let her be okay." And out of nowhere, this lady pops up in front of my face, and she says, "Everything is going to be okay. Your daughter is doing great. She weighs 5 pounds 14 ounces." Which was the same as my son. We just couldn't believe it. And she doesn't have to go to the NICU, which we couldn't believe that she wouldn't be going to the NICU. We thought she'd be under 5 pounds, and be whisked away right away, and she wasn't. You know, I was telling my mother my birth story with Lilah a couple of days later, and I said, "You know mom, I knew everything was going to be okay when I saw all of the nurses smiling, they were all smiling." And then I got my camera to show her, and there were 200 pictures on my camera that I didn't take, my husband didn't take. The doctor that performed the surgery took 200 pictures with my professional camera, but what I noticed about the pictures all of the nurses had masks, none of them had their face exposed. So why I thought they were smiling was so bizarre, and I was telling my mom this, and she's all, "Oh Leslie, it was all of the angels that were smiling down on you." And that's my story, and I believe it, and that's what happened. That day we were very blessed, and there were so many more souls in that room than just those nurses. And it was an incredible day. She did get diagnosed with achondroplasia that day, and by that point we were just like, "Oh, okay, great." It didn't feel bad like it did six weeks prior to that. It felt good to know that that was her diagnosis, and that she was going to be okay, and we were going to have a healthy daughter, and we were ready to move forward.

Gerald: That is great good story.

Leslie: Thanks.

Gerald: Thank you for sharing it. Um, what's been the hard part?

Leslie: Well, the hard part was six weeks before she was born. So, once we were in that dark place, it really did take us six weeks before she was born. We had to do a lot of soul searching in that time, and we had to dig really deep because we were really aware that we were struggling with a dwarfism diagnosis. So we were asking ourselves, "Why? Why was this bothering us? Why were we worried?"
And it went beyond her medical, it went beyond our concerns for her. A lot of it hit on social nerves, and that bothered us, that that was hitting those nerves. And so we really just went through this ugly grueling process of peeling back the layers of ourselves, and we started asking ourselves a lot more "why's" to get to the big why of, "Why is this bothering us?" There were really hard things that came up, like, "What are our family pictures going to look like? What are people going to think of our family? Are people going to be mean to her? Are people going to be mean to us? Is she going to be bullied? Is her, you know, quality of life going to be affected? Will she be sad, you know, will she wish that she wasn't born this way?" And we started getting all these really hard questions that, you know, were way down the road, but it still was our new reality. And so we just started pulling back the layers of ourselves, and realizing that we have work to do to not care what people thought. And that we were worried about people judging us, or feeling sorry for us, or putting us in a box that we didn't feel we belonged in, and that was the hardest process of shedding those fears and getting rid of all of the anxiety that came along with having

a child with this diagnosis. And we really wanted to just trust in the Lord and know that He made her perfect in His eyes, and we whole heartedly believe that. And so we really just want to trust His plan, and trust that He thought that we would be great parents for her. And so we went from being discouraged and frustrated and asking, "Why us?" There was a 1 in 20,000-40,000 chance that our child would be born with this. The odds for me were the same for you, and so, "Why us?" And so it went from that to a place of, "Wow, like, we feel honored that God chose us to get to walk this journey." And at that time, we wanted to really go through that process so that when she was born, we could be the best possible parents for her, and that she would feel nothing but love. And that her dwarfism diagnosis did not define her, and it was not whole heartedly who she was down to her soul. It's just a part of her, it's not defining for her. And so that was by far the hardest part, was just the work we had to do to get to a happy place, to have acceptance to move forward. And it's even more than acceptance. It's not just we are accepting this, it's we are celebrating her for who she is.

Gerald: So how old is Lilah now?

Leslie: She is four and four months.

Gerald. Four and four months.

Leslie: Five months, yeah, almost four and a half.

Gerald: So, tell me about the joy and impact that her four years and four months have brought to you, your family, your extended family, friends, neighbors. Tell me about that joy.

Leslie: Wow, that's hard to put into words. Before she was even born, we decided to let people know through an email, and I started blog and just wrote out her diagnosis and our journey with it. And we were very honest with the difficulty that we felt in the beginning because we didn't want others who were walking this path after us to feel like, "Oh, no big deal. We were fine with it. It didn't affect us, we were great from the beginning," because that was a complete lie. And we wanted others to know that it's okay to feel, it's okay to change, it's okay to be real with what's going on, but it's okay to allow yourself time to grieve and to heal. And so, when we let everyone know about her diagnosis, it was unbelievable the support and the encouragement, and just this huge village formed around us that I didn't know we would need, but we would desperately need. She had so many people that loved her before she was even born. It was incredible to know when she was born, it was like just this ray of hope for me and for so many others. I couldn't wrap my head around this child that was one day old, that affected and influenced people. Like she came here just as this, like, thing to be reckoned with. She was already well known, and just people adored her and I didn't see that coming. That was a huge relief for me to know that she was not only born into acceptance, but just massive amounts of love. But there is something that is so special about her, she just brings joy to so many people. I mean, just walking down the street with her is like having the rainbow follow you, because everyone smiles and I know they are not smiling at me. Just she makes everyone's day just by her being in their presence. And I wouldn't have believed it had I not been witnessing it for four and a half years, but literally joy follows her everywhere. And she has these eyes that are huge, and so wise, and I feel like she has so much wisdom behind them. And she always has, it's just all of these things I'm telling you about her personality, she's had from the beginning before we even got to know her personality. It's just how she came to this earth, just with this huge bigger-than-life personality. And it's almost just like God crafted this perfect person, and just knew exactly how to fit her personality with the dwarfism, and it just makes for the complete perfect package.

Gerald: That's super, thank you. Last question, if I came to you and said that we had received a diagnosis that we may have a child with this issue in utero, or let's say shortly after birth, what advice would you give me?

Leslie: I have had lots of momma's ask me that same question because of the blog that I had. I've been, I guess, contacted by women all over the globe asking me the same thing, "I just found out about this diagnosis, you know, I've read your story. I feel hope, but I'm still not okay. I'm stuck in a place of sorrow." And I tell them, you know, the same thing. I first, to be honest, I first ask about the diagnosis, if it's a lethal form, I handle it completely differently because there isn't a lot of hope with a child with a lethal form of dwarfism, it's devastating. I've worked with a lot of momma's that had that diagnosis, and so we talk a lot about preserving the memories with that child even though they are short lived, and just letting that legacy live on. And just really embracing the pregnancy, and just being at peace with that diagnosis, and just trusting in the Lord. That is a completely different route that I talk to with momma's that have the same diagnosis that Lilah has. When I find out that it's achondroplasia, I'm thrilled because the prognosis and outlook is wonderful. So, I'm happy for them, even though they are not happy, I'm very happy for them and let them know that. But I talk a lot about hope, and just about how mommas ahead of me in this journey told me that everything is going to be okay. And that someday you're going to look back on this and wish nothing was different. When I first heard that, I couldn't believe it. I just thought it wasn't something that I could relate to my life. It was surprising to think that I wouldn't wish something was different at the time, but not long after she was born, I felt that way and I believed it. And I encourage these momma's to really buy into that, and just really feel this way too, that your child becomes your child. And their personality develops and your love for them is so real and deep, and it's for who they are right then and there. And you don't wish that they were different. In Lilah's case, I feel like our world has been brightened 10-fold because of her diagnosis. I feel like it's added so much depth to our lives, and it's allowed us to become people that we always should have been striving to be, but didn't necessarily know that we weren't until she was born. And so, I really owe her so much gratitude, just by my own personal development. And so, I tell momma's that, and everything is going to be okay, and if they can believe that, then they can work towards healing. And then they can get to a place they do believe that. I also heard advice of just take one day at a time because I can tend to, and I think all momma's do this, but we look to the future and we worry about things like ridicule, and what's middle school going to look like, and what about prom, and will she be married, and what will mothering be like for her, and what will her challenges be? And you go to all these places that are so hypothetical and so far away that it can be overwhelming. But the truth is, I'm missing years and years of experience and wisdom and growth that I can't be possibly be ready for those experiences because I have nothing to do to look back on that will help me be ready. And so, I really have to take one day at a time, and know that today will prepare me for tomorrow, and I will get there when I get there. And we'll be doing all of this building day by day, and when we get there it will not feel so shocking and surprising and feel out of the blue. We won't feel overwhelmed, we'll have all these years of experience that we'll have to draw upon in that moment. And so, when I get overwhelmed and I find myself looking into the future, I just stop myself and just know that we'll get there when we get there. We're not there yet, and so I tell momma's the same thing, just don't go there, don't allow yourself to go there. Just enjoy what you have now. If something comes up, just deal with it in the present, and don't think about the future it in terms of being overwhelmed.

Gerald: Super, thank you.

Leslie: You're welcome.

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

Leslie: Of course.

Gerald: It's awesome.