

An Orange Socks Story - Kelly and Zac: Achondroplasia
Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I appreciate Kelly and Zac taking the time for an Orange Socks interview over the phone about their son, Everett, who has Achondroplasia, a type of dwarfism. Kelly and Zac turned to God for understanding and comfort, and now recognize the blessing Everett is in their life and those around them.

Gerald: Kelly and Zac, thank you so much for taking the time to meet with me and do an interview about your son Everett, who has Achondroplasia. Kelly, when did you find out Everett had Achondroplasia?

Kelly: Gerald, thank you so much for having us. It's an honor to share about Everett. Everett was about six weeks old when we found out. We had not learned his diagnosis in utero. We had only one ultrasound right around the 20-week mark, and everything seemed to be normal. They called us to come back and do another ultrasound because they said there were a few measurements that they needed to get again so we went back within four weeks. It sounded like the measurements they were after had more to do with his body position keeping them from getting the measurements they needed, and nothing was ever mentioned about anything proportion wise with his body. They just said his head was measuring rather large, but we didn't really think that was a surprise at all. When he was two or three days old and we were getting released from the hospital, the pediatrician who was doing the discharge actually came in to chat with us. We were packed up with bags in the car waiting for Everett to be brought to us so we could leave. It was interesting the way the pediatrician phrased it, she said, "Have you noticed that Everett is unusual looking?" I was actually offended. We were caught off-guard and said, "No, we think he is beautiful and looks like a very healthy beautiful newborn baby." She first proposed skeletal dysplasia, then she said achondroplasia. I had never even heard that word before. I remember after she said it, I just went blank and nothing else sunk in, but thankfully Zac was able to listen a little bit more and translate for me after she left the room. The next week, our regular pediatrician said, "I heard what happened, and I do think that we should go to the children's hospital and have some blood work done to see if this is actually the case." The next week we went to the children's hospital and did the blood work. It wasn't that we were in denial, but we honestly did not think that it was even a possibility. Then we got the phone call a few weeks later where they confirmed the genetic diagnosis of achondroplasia.

Gerald: Zac, what were your thoughts when you got a definitive diagnosis that your son had achondroplasia?

Zac: It was really just heavy. Everything just kind of stopped. At age 37 and this being my first son I'd waited my whole life for, I envisioned this child to be perfect and beautiful and joyous. Then we received a diagnosis that has been tested and proven that basically derailed our mortal interpretation of what perfect looks like,

or what average looks like. It was hard for me. It was a lot of pleading with God to take this from us. I did not want our child's life to be harder than what mine has been. I'm what the world would consider a person of average height and average intelligence, and life has been hard enough just as a regular citizen of the world, so your mind starts to really go much further down the road regarding what it's going to be like for your son who will have this diagnosis. It was a lot of wrestling with God over that.

Gerald: So, Kelly, tell me, what have been some of your challenges with Everett?

Kelly: Challenges like in the standpoint of physical or just with the diagnosis?

Gerald: Both. Maybe expand upon what Zac said about accepting it, and I guess about caregiving or whatever that comes to mind about what's been hard about this for you.

Kelly: One of the things that was most challenging from the get-go was that it did take us a little longer than we hoped to conceive. We are a little bit older, and when we were finally pregnant for the first time, my pregnancy was an absolute joy. I loved being pregnant. Some people thought I was crazy and didn't relate to it, but I really, really loved it. It's the most beautiful experience. You can't help but have dreams and visions and hopes for all the things your child's going to be. After that initial diagnosis was confirmed, my mind immediately went to other thoughts. I felt like I was also very average height, average build, average athleticism and all those types of things. I endured a lot of hardship growing up. We moved a lot, and at times, I felt grief and was ridiculed, so my mind immediately went to that place where the world can be very cold and hard. The expectations of success and what beauty is and all these things are very challenging, so I immediately grieved. I thought at that moment that life was going to be that much harder, and that was challenging. We immediately turned to God in prayer, which brought up a whole other challenge of wrestling with God, like Zac said. Okay, God, what does this look like? I believe that Jesus bore so much, and there's so much that can happen in terms of healing and fulfillment and restoration. There was a lot to work through prayer with God as to what this looks like. There was a lot a lot to learn as far as what kind of complications can come with this diagnosis. The first things we learned about involved hydrocephalus, a build-up of fluid on the brain. The doctors prepared us for those things, explaining that was a possibility. We did an MRI when Everett was just a couple of months old. We had to go to the children's hospital which is about three hours away. For me personally, my labor and delivery was extremely challenging. I had a forty-six and a half hours of labor that also included two hours of pushing before we realized that there was no way I could deliver him like that because his head was so large and my opening was too small. That resulted in an emergency C-section, so the recovery from that long labor, that sort of physical exhaustion, paired with the surgery was extremely challenging. Then navigating the new things of parenthood with lack of sleep and breastfeeding and then having multiple doctors' visits, getting in the car and traveling, to be honest, those things I

found to be simple were extremely challenging. Then trying to manage the thoughts, “Oh, my goodness, does our son have hydrocephalus? Is this narrowing of his surgical spine moving the brain stem? Is this going to cause problems that are going to require decompression surgery? Are we going to need a shunt?” Those types of things were proposed, and they were so heavy that all we could do was just turn to God in prayer and plead for Him to work in Everett’s life and just trust in Him, and that’s what we did. It gave us peace and understanding. We found that we just had to take the challenges day by day, and every day God provided enough peace and enough mercy where we were able to make it through.

Gerald: That’s super.

Kelly: We also were able to experience the joy of parenthood. We were so in love with Everett that it dissolved the fear that came along with that.

Gerald: That leads into my next question. Zac, what have been some of your joys in having Everett in your life?

Zac: For me, it has been wonderful to experience the responsibility of caring for Everett. Once I embraced the realization that God has entrusted us with something that is going to be impactful in other people’s lives, it’s the story of this person who is just as human as you or me, and who has a whole world out there to discover and to impart things to me. That’s a different way of looking at it. I never would have looked at it that way, so those realizations are exciting, they bring you hope. I remember on several occasions sitting around the dinner table with other couples who were talking about their sons and how good they are at athletics. Athletics was a great way for me to connect with my grandfather and my dad, and I’m realizing that my son is going to be interested in other things. I have no idea at this point if it’s coding or video games, it will just be different. It’s not any less of a life or any less of a level of enjoyment and joy, it just comes packaged differently. For me, that’s been the shot in the arm. Every day when he looks at me and smiles and talks to me, it’s incredible. The reality is that Everett is vertically challenged. Everett is cognitively progressing and physically progressing. His motor skills are intact. For all intents and purposes, he is a perfect little boy, just more little.

Gerald: Kelly, what are some of your joys?

Kelly: The first day he was born, our doctor encouraged as much skin to skin as possible, and I cannot quite explain the feeling of peace and joy that brought. It’s almost a chemical thing that happens in the brain. I don’t think I let anybody hold Everett the first 24 hours; I was completely selfish. Family came to visit, and I told them that they could hold him tomorrow, and I would never have to say that again. It was the most beautiful thing that I can’t quite put into words. In the gospel of Luke, he talks about how to ponder these things in your heart, and I think about so many things. It’s almost like God hasn’t given me the words to express because it’s so private and impactful on my heart that I can’t even put words to it. The things

that I can put in words are watching him grow, watching him start to do the physical motor things and the things that I read might be challenging or take more time for him. Everett is in physical therapy once a week, and he also does developmental therapy twice a month. The therapists come to our house and work with him, and then all of a sudden we see him start traveling around the furniture or taking a step or babbling words. The little developmental things are awesome to me and so exciting just because we know that we've been told it might take a little bit longer and may be a little bit more challenging. Everett's personality is one that is extremely full of determination. He is driven and kind of head-strong, and I'm thankful that God instilled him with those things because I know that they are going to take him far in life, and that gives me joy that I can't describe.

Gerald: That's great. Tell me a little bit about his impact on your family, your extended family and friends, and then when you're done, Zac, if you want to add to that, that would be great.

Kelly: Everett is the first grandson on both sides of the family. He has been long-awaited, so when he came, everyone was overjoyed. Of course, they had to sit in the hospital waiting room for way longer than they anticipated, but I think the anticipation grew the excitement even more upon his arrival. I think there's something pretty special in that A, we didn't know about his diagnosis prior to his arrival, and B, we decided while he was in utero that we didn't want to know the gender. There was just so much more excitement around the whole experience. Our family has been extremely supportive, both sets of grandparents. Zac and I both have siblings, so Everett was welcomed in by aunts and uncles and family who were extremely loving, supportive and in awe of him. They see the beauty in him. Upon finding out about the diagnosis, there were initial fears and concerns about what that meant for his life. None of us had had any experience with any form of dwarfism, so we didn't know if that came with any pain, any complications or life expectancy. As soon as we were able to ask those questions for clarification and realize that those were not going to be challenges for him, I think everybody kind of breathed a sigh of relief. I will also say that we kept things private. We did really few things with our immediate family for a while so that we all had time to digest it. We all had time to thank God and understand His viewpoint to really share with a lot of other people, which I think was a unique bonding experience for our family.

Zac: I really don't have anything to add to that. Obviously, with our families not having any prior experience, it really was a waiting game, wondering if typical complications with achondroplasia were going to be fatal. Once we were given the green light to go about our daily lives, certain as we always have been, I think our entire families just kind of breathed a sigh of relief. From that point, it really is just making sure Everett's identity isn't founded in his diagnosis and that he is recognized as a normal person for two families that have never experienced that and our extended friends. We've talked with our pediatrician here, and there are no other families in Northern Arkansas that they're aware of. There used to be, but they moved on. There's a group in Central Arkansas that would be a great resource for us.

It has just been a matter of slowly wading into the waters of the world of achondroplasia with our friends and family, and everyone has been incredibly supportive. Everett has more followers on Instagram than I did for the first five years that I was on there. I mean it has just been incredible.

Gerald: You can talk first with this Zac. If I just found out my child has achondroplasia, what advice would you give me?

Zac: My advice would be to spend some time in prayer. You are probably walking through an unbelievable stormy ocean of fears and worry, and I know you're borrowing trouble about tomorrow, about some things that you just assume. Take refuge in what God says about His creation and what He says about His plans for you. That's where you will find the stillness and the peace that is beyond your understanding. That is where I've had to go until I felt like I could handle it, where I felt like I could process this and begin to move forward with what the new reality looks like. If I didn't know God or know what a relationship with Him looks like or what He said about His plan for us, that the plan is not to harm us but to give us hope and a future, if I didn't have that kind of scripture tucked away in my heart, I am not entirely sure how I would have managed the first six months to a year with Everett. The human condition is to borrow what I consider trouble from tomorrow about things that you don't even know. Worry about all you can concern yourself with today and about what is on your plate today.

Gerald: Kelly, what advice would you give?

Kelly: Take the doctors' recommendations and look into things, but don't take it as the final word. That was something that we agreed upon, that God has the final say in every reply, and we want to be responsible parents. We want to take all the recommendations as far as having this surgery done, having this checked out and it's better than we thought. We also don't want to take it as the final say as God has the ultimate truth. I also would recommend; in the beginning we did not do a lot of Googling. We did not do a lot of searches on our own to find information because I didn't want this to take over my life. I wanted to love my son and get to know him. First-time parents especially have so much to figure out, like the basics of feeding and sleeping and changing diapers, a new schedule and a new life and even our new identity as parents. I did not want to turn into a person constantly trying to find things out, I wanted God to present those things to me. I took my time and slowly started to build a community with some people who have a similar diagnosis. I am very thankful for Instagram and the internet. There are Facebook groups that you can join so that you can build that community, and they provide a lot of stories of hope. The doctors are going to give suggestions and recommendations, and sometimes they have to give worst-case scenarios. It's really great to find people that you can build community with who have had very hopeful outcomes. I think it's really important. Just be careful what you fill your mind with and take things one day at a time. We also blanketed ourselves in scripture, which I feel has the ultimate authority and truth in our lives. We leaned very heavily on what God says regarding

this situation and made it the ultimate source of truth as opposed to opinions and things of the world. That gave us a lot of peace day by day. Very simply, I would say how blessed are we, the lucky few to whom God has entrusted a special gift. It's going to open our eyes and broaden our lives in such a meaningful way. I'm ecstatic that I'm getting to be Everett's mom. I would tell someone that it's going to be scary, but it's also going to be full of joy and a whole new experience that you could never plan for.

Gerald: That's awesome. You guys are great. I really have enjoyed speaking with you. Any final thoughts from you, Kelly, or from you, Zac? Kelly, you can go first.

Kelly: My final thought would be that nothing is an accident. I don't believe in accidents. I think that God ordains our steps, and I think everything He makes is beautifully and wonderfully made. Everett came at a time in our lives when we were actually told we would have a hard time conceiving on our own, and then literally the very next day, I took a pregnancy test that told me we were pregnant. Throughout the pregnancy, I had vision of a lion being strewn about, then Zac said, "I would really love it if there was a lion in the nursery." We had not had the discussion at all, but God put the vision of a lion in our hearts. We also had a girl name picked out, but we had a hard time coming up with a boy name. It was like neither one of us had any ideas. I'm a hair-dresser, and one day I was doing hair, and all of a sudden, the name Everett just popped in my head. Later we found out that name means brave, so I thought, wow, we don't know the gender but I'm almost 99% sure that it's going to be a boy and that his name is Everett. God has given us the vision of a lion, which is brave, and there is going to be something special and unique about this child. He is going to do great things. I loved having all these reassurances from God, it just gave me confidence that He is in control and He has the story planned. That's been the most incredible experience. It has been super humbling and has drawn me closer to Him. It makes me extremely excited about the future and all the things that He's going to bring to our lives.

Gerald: That's great. Zac, any final words?

Zac: I really don't have anything to add. Kelly has done a marvelous job of encapsulating our story from front to back. I would definitely encourage those who are just swimming in it and don't know where to seek counsel that they seek that from a community of people who have received the same diagnosis. If they don't know the Lord, I would encourage them to find a local church and find somebody who they've always looked to in that regard, because it definitely calms the waters. It will begin to transform your mind into one of gratitude. You'll be able to enjoy the gift, the miracle that God has given you. I truly believe having sat on this side of the fence, no matter where or what your child's diagnosis, even if it's terminal or complicated or perfect, whatever the word, "perfect," means, there is a reason for that life to have come across your path. It may not be revealed to you as quickly as you would like, but I truly believe one day God will reveal the purpose and the plan

for that life having been in yours. You just have to stay faithful and committed to raising your own human.

Gerald: That's great. Thank you both.

Kelly: Thank you for having us.

Zac: Absolutely.