

## An Orange Socks Story - Rebekah and Chris: Achondroplasia

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was honored to go to the home of Rebekah and Chris to have an Orange Socks visit about their daughter, Ella, who has achondroplasia, a type of dwarfism. Rebekah and Chris also have dwarfism, and I appreciated their candor and insight.

Gerald: Rebekah, when did you find out that Ella had dwarfism?

Rebekah: We found out at 24 weeks in utero. We had done an amniocentesis, and we knew that we had a chance of having a baby with dwarfism because Chris and I have dwarfism, and we wanted to know. I don't like surprises. I have to be prepared. With our chances of having a baby with dwarfism, and of having a baby that is a double-dose of dwarfism where they don't survive long outside of the womb, I needed to know what to expect and prepare myself for that situation. Either way, we would have taken any type of diagnosis we got as we were going to take this pregnancy all the way, but we just wanted to prepare because I didn't want the unknowns. We found out at 26 weeks that we were having an achondroplasia dwarfism child, just like Chris and me, and we were excited.

Gerald: Your chances of having a child with that diagnosis are at what odds?

Rebekah: There was a 50 percent chance for a child like Chris and me, who both have dwarfism, and a 25 percent chance where the child does not get the dwarfism gene and be average size. The other 25 percent is where they get the double-dose of dwarfism, and those babies don't last very long outside the womb. I've had friends whose babies had the double dwarfism, and they might last for a day or five minutes to a day, and then they slowly pass away. I felt I needed to be prepared for that.

Gerald: Chris, what were your thoughts at the time when you found out you were going to have a child with dwarfism?

Chris: I was scared to tell you the truth, because during my life, I was small. I think it's different between the boys and the girls with dwarfism. I don't know why, but I thought that Ella might get made fun of a lot and stuff like that. I was excited to have a little one just like me and everything, but again, it was a surprise. I was happy at the end when she was born.

Gerald: Well, you had some personal life experiences that sound like were hard for you because of your diagnosis of dwarfism.

Chris: Kind of a hard time, not really hard, but different.

Gerald: Sure.

Chris: And especially around high school and junior high.

Gerald: That's a tough time for a lot of people.

Chris: Yep, it is.

Gerald: It sounds like it was a trial as a male with dwarfism.

Chris: Yeah.

Gerald: Did you have any issues like that?

Rebekah: Oh, yeah.

Gerald: Okay.

Rebekah: What prepared me the best is both of our parents who were involved with other parents who have kids with dwarfism. Little People of America is a great organization, and they got us involved in that, so we were able to make friends with our peers who were people with dwarfism our age. We were able to identify with that and also have mentors who were little people who would tell us what to expect instead of having an average-size person say that it's going to be all good. It's going to be hard, but you can get through it. A little person mentor tells you this is what's going to happen, it's going to suck, expect it and it's okay.

Gerald: Sure.

Rebekah: You will get through this. High school is not your whole life, junior high is not your whole entire life. As a teenager, you think that's your whole entire life, but I think what helped me a lot was being prepared for that, knowing that I'm probably not going to be asked to go out to dances as often as the other kids, and I probably won't have as many friends that will call me. We were popular in elementary school, we had lots of friends, but when it was time to hang out as a group, you weren't called that night to go hang out. You had your close friends, but when it was a group, you really weren't called that much. It was setting that expectation, and it was hard to go through. I think what our parents did best was helping us understand who we are, living with dwarfism and knowing that we were the ones who defined who we are, and not the people around us. This was before we had Little People Big World, or understanding what little people are. People would call us midget people and make fun of us openly. It happens a lot less now, for which I'm grateful, because of laws, Little People of America, the educational shows, and nonprofit organizations that get the word out, but going through that was hard.

Chris: It was also hard for my brothers and sisters, because we always got that attention. Sometimes adults would give me something and not to my brother or

sister, so then they would feel bad. I would feel, "Yay!" But to have it was kind of like, "What?"

Gerald: Interesting.

Rebekah: Yeah, that does happen, you get parents.

Chris: Yeah, that even happens to this little one.

Rebekah: Yeah, it does.

Gerald: Well, your personal experiences have kind of enabled you to get an idea of maybe what Ella's life is going to be.

Chris: Yeah, exactly.

Gerald: What so far have been some of that challenges now she is five years old, and what have been some of the hard parts with Ella and her life so far?

Rebekah: I was really protective of her. When Chris and I were walking down the street with a baby stroller, I would put the curtain down, because when people saw us, they would turn around and look in because they wanted to see the child. We were asked quite a bit, "Oh, can we see your baby?" It was hard sometimes.

Chris: It depends on the people.

Rebekah: If it was kids, I was totally fine, and I would make it an educational moment, but if it was a young adult or an older teenager, I'd say that she was sleeping. I didn't want to show her because I knew they just wanted to see.

Gerald: So, it was more like you were on display.

Rebekah: If they did have questions and if they did come up and start asking questions about us, wanting to know about our dwarfism and who we are, of course we'd show you the baby. I didn't really realize how protective I was. After she was born, I was going to my mother a lot, asking her about development and what are the milestones, what do I need to do with this appointment, etc. I didn't really do research about how we needed to follow this or follow that, because I thought that since I have dwarfism, we're fine and I'll know what to do, but I didn't know what to watch for, so I went to my mom a lot for advice. I was also on the Facebook pages of parents with dwarfism and parents of dwarfism children and getting those questions answered. I thought that was kind of interesting because I thought that I should know this, but I don't because I did no research. Getting to be a part of those Facebook groups of parents with dwarfism children helped a lot, just asking those questions.

Gerald: Are there differences developmental milestones with someone with dwarfism?

Rebekah: The good thing about it is that they don't walk until around two years old, and by the time they are that age, they know.

Chris: What's right.

Rebekah: What they can't touch.

Chris: And what's wrong.

Rebekah: It has been nice that we didn't have to baby-proof at all. That was a stark difference between our son and her, I didn't have to baby-proof anything, whereas with him, I was always chasing. He could walk by 18 months, and she could walk by three years old, it all depends. She didn't sit up until the age of one, and you don't want to force them to sit up, you kind of let them do their thing.

Gerald: Sure.

Rebekah: They are just a little bit slower developmentally, but ahead socially because they are not busy running around being a busy toddler. They have that time to figure people out. With Ella, what was interesting was that she was able to engage people with a smile and say, "Hi," and so she's socially ahead. She knows emotions and was able to concentrate on that while this other stuff caught up a bit. Now she's basically all caught up and just has to do things a little bit differently. Of course, she can't run faster than her peers, but she's able to play soccer and she's able to do what she wants to do.

Gerald: That's great. Chris, what have been some of the joys of having Ella in your life?

Chris: Oh, boy, too many joys.

Rebekah: I think it's just like any child.

Chris: Especially when Rebekah was pregnant, we were trying to think if it was going to be a boy or a girl, and I wanted the boy and she wanted the girl. When we found out it was a girl, I was like dang it, I wanted my boy, but then It has been a blast. She always wants to do what I want to do. I'm into hunting and guns, and she likes to look at my guns.

Rebekah: She's daddy's girl.

Chris: She's daddy's girl, that's for sure. She has me wrapped around her finger and everything.

Gerald: So, Rebekah, what has been her impact on your family, your older son as well as your immediate family, and with her coming into your life?

Rebekah: It's hard to say on that, because it's almost like another child in a way. Yes, she has dwarfism and she'll probably have some medical needs, but we wouldn't think of her any differently.

Gerald: Right.

Rebekah: She has just scooted on in on both sides of the family, she's not treated any differently.

Chris: No.

Rebekah: And we don't treat her any differently than her brother.

Chris: Yeah, treated her the same.

Rebekah: That's how we were raised, so I think both of our parents were excited that they were having a little girl with dwarfism because they stay small so long.

Gerald: Yeah.

Rebekah: They were excited about that. I don't know if her personality is because of the dwarfism, but it's the personality that I adore. I don't know if that's the dwarfism or if it's just Ella. That has been the biggest impact. I don't know if it's siblings or what, but her brother has a hard time socially, and she's able to understand and have patience with him. He is able to interact with her, and they've built a trust with each other. It's a sweet relationship between the two, a connection.

Gerald: And he's about 11 years older?

Rebekah: Yes, he's 16.

Gerald: So, he's quite a bit older than her.

Chris: I'd have to say it was hard on Ryan a little bit.

Rebekah: At first, because he was the only child. Of course, they fight and have their interactions, but it has always been a strong connection between the two.

Gerald: And both of your sets of parents were normal-sized.

Chris: Yeah, both normal.

Gerald: And it sounds like they were awesome.

Chris: Yes.

Rebekah: Yes.

Gerald: It sounds like they were great and are wonderful grandparents to Ella.

Chris: Yeah.

Gerald: If I were to come to you just having received a diagnosis that I was going to have a child with dwarfism, what advice would you give me?

Rebekah: What always comes to my mind hearing about when my dad was told the diagnosis was his first thought, "Who is going to take her to prom?" That was his first thought. That's a lot of people's thoughts about all the unknowns and what's going to happen. The best piece of advice is to find as much information as you can and seek out other people who have the diagnosis, parents as well as adults who have the diagnosis. That's going to be your best bet because you're able to see where they are and how they got there and what to expect. Just reach out, which is what my parents did. They were given a phone number because back then, there was no internet and no Facebook. There was nothing except for a little pamphlet that says your child has dwarfism and just the basic stuff, and they were told not to expect much from this child as she is going to be made fun of, and all they'd seen were dwarfs in circuses and on shows that are presented in a derogatory way.

Chris: They look at us as animals.

Rebekah: That's what they would say, but nowadays, I'm grateful for that getting better. Just seek out Little People of America and get your child and your family to be a part of that organization. My average-sized brothers and sisters have benefitted from that too. Our summer vacations were going to the national conferences, and my siblings were able to make friends with other siblings and other little people, and they were able to share their stories about how their siblings with dwarfism get all the attention. Our parents tried to not do that, but it happens. I would just tell that parent that it's going to be okay, enjoy life because you're going to be opened up to a whole different world. You're going to be meeting so many different people because of dwarfism and seeing that from a different perspective.

Gerald: Chris, do you have anything to add to that?

Chris: No, I think Rebekah said it pretty dead-on.

Gerald: Okay, good. You guys are awesome. Any final thoughts that either one of you have?

Rebekah: One final thought, I love it when kids come up and ask questions.

Chris: Yeah.

Rebekah: I love that. I'm trying to teach them not to tease.

Chris: Ryan teases the kids a lot.

Rebekah: Yeah, he does, but I love it when the parents or the kids ask questions. The parents will bring up the kids and want to ask questions, I think that's wonderful. When you get into a situation where you're at the grocery store with your child, and your child just points and yells, "Look at those people!" and you want to say "No, don't do that." I've seen a couple of parents who would smack them like don't do that, and I know it's I mean and that's not good manners, but please explain to them that it's okay to ask questions. I find that when the parents don't explain what's going on, it gives them that fear of that difference.

Gerald: Sure.

Rebekah: I love it when kids get up and ask questions and want to know, and once they know, they are okay and walk away. I love it. I think it's great. With Ella being a child with dwarfism and us as parents having dwarfism, in a way, it's good, but in a way, because she has us as parents, I think once she gets more out into the world...

Chris: ...she'll recognize it.

Rebekah: More because her parents have dwarfism, but it'll be interesting. I just want to raise a competent child who knows who she is. Dwarfism is a part of her, but it doesn't define her. In our lives and in our work environment, first you're a little person with dwarfism, and then you have to show them who you are.

Chris: You have to show them what you can do.

Rebekah: At times, that's a struggle, but that's just what it is.

Gerald: Yeah.

Rebekah: You just have to say, "That's who I am. It doesn't define me. It's a part of me, but it's not who I am."

Gerald: Well, great.

Rebekah: I'm proud to say it.

Gerald: Ella's delightful. You're a doll and what a blessing for your family to have her in it. Thank you, guys, for taking the time.

Chris: No problem.