

An Orange Socks Story – Kecia and Kris: 3 children with Down syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I am grateful to Kecia and Kris for having an Orange Socks interview with me. I appreciate their honesty in sharing their feelings about their experiences with their daughter, Brie, who has Down syndrome. Kecia and Kris' story is unique, because in addition to their five biological children, they adopted two other children from the Ukraine with Down syndrome. I know you're going to love listening to their wonderful story.

Kecia: We had two daughters who were typical, healthy children, and then we had our third daughter, and did not know anything was wrong until she was born. I had her via C-section, and I didn't think anything of it when they showed her to me. I didn't really recognize any difference, but all the nurses and doctors acted funny, I guess, kind of whispering in the corner and being a little strange. They took her away and then brought her back into the recovery room, and that's when the doctor said, "I think your daughter has Down syndrome," and that's when we became super emotional. My husband said he knew right away when he saw her that she had something different, and so we were scared, and there were a lot of unknowns. The first thing that came into our minds was the thought of all the things that she would not be able to do, not all the good that she was going to do. I felt like that was all I was able to think about. She's not going to do this, and she's not going to do this. She's going to be different from my other girls, and worrying about all the "what if's." And her health, of course, was a concern. She did not end up having heart problems, which was good for her. We started that journey and found out pretty fast that it was not scary at all. I was pretty nervous about dealing with Down syndrome. I didn't know anyone who had a disability. In high school, it wasn't really a common thing. It was all new to me. I remember they took her away to the nursery for about 20 hours, and since I had a C-section, I couldn't see her for a little while, and that whole time I was just scared. But then when they finally let me go into the nursery to see her, and wheeled me up in the wheelchair next to her bed, I just remember she was in this little incubator and she just wrapped her little finger around mine, and I knew it didn't matter what she had going on. The challenges that she was going to bring to our family or for herself didn't matter. We were going to be okay, because there was something really, really special about this little girl. I could feel that from the first second that she held my hand. There was still a lot of emotion for those first few months, but we knew we were going to be okay. There was a reason that this little girl was in our lives and that she came the way she did, but we had no idea that it would turn out the way it has.

Gerald: So, Kris, what were your thoughts when you realized that this baby had Down syndrome?

Kris: It's interesting to remember back to those moments when you find out that your child is different. The first thought that I had was just overwhelming. It was hard to even understand what that really meant. I didn't really know much about Down syndrome or its specific challenges. All I knew is that this was something that was different and was going to be hard. I remember feeling very scared as a dad, especially worrying about how I was going to protect this little girl, how I was going to watch over her. I knew how some of these kids were treated and things that were said at school and other places, so how was I ever going to feel okay sending my little girl out the door into the world to be made fun of? As a father, that was hard to try and understand how that would happen. A lot of the feelings the first few days were centered around how we could fix this. How can this be overcome? I remember a lot of our family said things that made us feel like maybe this will just go away or something, and you quickly realize that this doesn't go away. It's not something that just comes and goes. So, to spend those next few weeks and months with my wife learning about the challenges we had in store was a scary time. However, it didn't take long until we realized that she was just a baby. There wasn't that much different about her when she was home. She was a little baby, she cried like a baby, she smiled like a baby, she cuddled like any of our other babies. You quickly realize that life goes on, and that life is more normal than we ever thought it would be.

Gerald: Kecia, what have been some of the challenges that you've had with her, and we'll talk about your other children as well, but specifically, what challenges did this bring into your life?

Kecia: You have to change your idea of perfect and your idea of what the norm is. You have children, and you think, "Okay, they're supposed to do this at this age, and they're supposed to do this at this age, and it's supposed to look like this," but with Down syndrome, that's not how it is. She did all of those things. She walks. She talks. She did all these things, but she did them all in her own time, in a little bit different way. One of the things that I think was the biggest adjustment for me when she was really young was just trying to let go of that comparison. Her typical peers are able to do certain things, and she's not able to do those same things or in the same way. It's difficult. I think it's gotten easier in some aspects as she's gotten older. I've gotten more used to that, or just kind of come to realize that she has her own normal, but I still have moments where I think, "Oh this is hard. Why should she have to struggle this way? Why is putting on her shoes and doing up her coat so hard for her when it comes so easy to a typical child?" There are challenges as far as speaking, having a harder time communicating and a harder time expressing her feelings. I think one of the biggest challenges for me as a mom to watch is when she can't express what's hurting her or what's bothering her at school. If she comes home and is having a rough day, she can't explain to me the scenario of what happened and why she's upset. It's hard that you can't work through those things the same way as you can with my typical children. At the same time, there's so much about Brie that's so amazing that even those challenges have just become part of who she is, and I don't know that I would trade it.

Gerald: So, Kris, what's been the hardest thing for you?

Kris: Like Kecia said, most of the challenges come in the way of communication. One challenge is not always being able to understand what they need or what they're wanting or what's bothering them is a challenge. You always want to watch over your kids. You want to make sure they're comfortable. You want to make sure they have what they need, that they're not in pain or anything like that. Some of those times, not knowing what they need is the hardest thing, I think. It's interesting that many times whenever we talk with other families about Down syndrome and our kids, the conversation is driven by challenges, about what's so different and what's the hard thing about having those kids. I often think that I could sit here and talk to you for an hour about the challenges of each of my kids. My oldest daughter, my second oldest and my youngest have just as many challenges in their life like every kid. The challenges are different because of the special needs, but it's not like other kids don't face challenges too, it's just a different set of challenges. That's what we always try to talk about with people. No kid has a perfect life. Every kid struggles in different areas of school. Brie and Mia have a harder time writing and reading and doing math, but some of my other kids are good at English, some are good at math and other ones aren't. It's just interesting to look at all of your kids and know they all have challenges, but the beauty of Brie and Mia and Down syndrome is that the benefits that we see as a family far outweigh the challenges that we face.

Gerald: Along that line then, tell me about the joys.

Kris: We could spend days talking about those. Brie has always been someone special in our family, she's kind of the peacemaker of our home. She's always had such a sweet and tender spirit. She doesn't like it when it gets loud and confrontational. She's always been the person that calms the mood of the house down. If you ever meet her, she'll be the first one to just run up and give you a hug. We always talk about that. If you're having a bad day, all you need to do is come home and get a Brie hug because it just helps you to feel better. It has been an amazing journey over the last 10 years since she was born into our family. A lot of the opportunities that we've had as a family have come because of who she is and because of the relationships that we've been able to form that often wouldn't have been formed. You can't really go many places with her or with any of our special needs kids where you don't meet someone with whom we've formed an instant connection.

Gerald: How about you, Kecia? What are your joys?

Kecia: What Kris said is definitely one of them, just that ability to let things go. Brie in particular has really taught us about loving unconditionally. When she was little, I had her at the park, and she kept walking up to this group of big, scary-looking guys who were working on the plumbing system, and I was trying to

keep her away from them, and she kept insisting on going over there. She finally got away from me and walked up to this one particular guy and just gave him a hug. He was digging in a hole of dirt and kind of just looked at her, and he just got a little bit tenderhearted looking at her. She just smiled and walked off. She's just always had that ability to know that somebody needs that for whatever reason. The joy of watching that and being able to live with someone who exemplifies that attribute is hard to express in words. I think it just continues to teach us what's really important and that we focus so much on things that are not what life's about, and she really just keeps us grounded and reminds us what life is really about.

Gerald: So, you guys expanded your family, too. You had some adoptions. Tell me about your adoptions.

Kecia: When Brie was a couple of years old, we wanted to have more kids. We started trying to add to our family and had a couple of miscarriages, and our third one was really hard. After that, we kind of just thought, "What are we supposed to be doing? Where is our family supposed to be going?" We felt like something was missing. That was kind of when the adoption thought came to mind, but when we brought it up, we thought, "Well, why would we adopt? We can still technically have our own children biologically?" So, we kind of pushed it aside a little, but as we started opening our minds to that, we found a picture of our now daughter Mia on the internet. She was living in an orphanage in the Ukraine, and I think one of the reasons that her story grabbed us was because she was the same age as our daughter who had Down syndrome. She also had Down syndrome, and she was given up at birth for that reason. As soon as her parents found out that she had that, they left her at the hospital and never looked back. She spent four-and-a-half years in an orphanage, not being allowed to play outside, not being allowed to really even get out of a crib for very long. She was not able to communicate or express her thoughts, and as I look back at that, I think that not only did I immediately feel like she was supposed to be with my family, I also had an additional attachment because I knew what this meant, that she had Down syndrome, and that she could have been my child who was suffering and alone, merely because she was a little bit different. Had we not had Brie in our lives, we wouldn't have had those same connections to this little girl. We adopted her in 2011 and brought her home. In Eastern European countries, when they turn four or five, they're moved from the baby orphanage to an adult mental institution, so she was just a couple of weeks away from that. They decided to hold onto her because we were coming. With her, we felt pressed to get to her to keep her from that future. We brought her home in the summer of 2011, and a week later found out we were pregnant with twin girls, so that made six girls. We had a rough time with the twins. They needed a life-saving surgery when they were in utero, so at 20 weeks, they flew us to California for a surgery that saved their lives. They had something called twin-to-twin transfusion syndrome, which meant that one was living off of the other's nutrients, so they both would have died in a matter of weeks had they not been able to do this surgery. Here we had this new little girl from Ukraine trying to figure out what a mom and a dad and family is, and then I was put on bed rest for the next five months of that pregnancy. But it worked, and the twins were born healthy, and they're as lively as ever. They'll be five in a couple of weeks. Then last year, we thought we were good, we had six girls, two with special needs. And then last year, I started to feel a little bit differently again and started to feel something pulling me towards adoption. Long story short, those feelings led us to another little boy in Ukraine. He was also given up at birth because of Down syndrome, and when we found him, he was 10 months old and living in an orphanage as well. His story was a little bit different, and we had a neat experience getting to learn more about him and meet his birth mom when we traveled to get him. His birth mom would have kept him. I remember that she said when he was born and they told her that she could not keep him, her husband said she had to choose between this child with Down syndrome and him and her other son, mostly because of the culture there. There are no resources or acceptance of any kind. It's really just black and white. If you have a child with Down syndrome or special needs, you give them to an orphanage. That's just how the thinking is. She had a really hard time with that, and she said that she kept thinking, "Why didn't I know before that he had Down syndrome, and why didn't I know when I was pregnant with him?" She said, "Now looking back, I realize it's probably because I would have aborted him and not have chosen to keep this child." She can see now that he is so capable and has the chance to be in a family. She loved him a lot, but knew she couldn't provide what he needed, so she left him in the hospital and prayed every day that someone would come find him. That's how we found them.

Gerald: So, Kris, you have two adopted children with Down syndrome and a biological one with Down syndrome, and you have how many others?

Kecia: Four.

Gerald: All of a sudden, I lost track. Perhaps this is a loaded question, but what impact have the children with Down syndrome had on your family, both your immediate family as well as your extended family, and maybe even your friends? What's been that impact?

Kris: That is an interesting question because I don't know if we even know the impact that Brie has had on the world. For us, Brie opened our hearts and our minds about what Down syndrome was to the point that we chose Down syndrome two other times. We chose to adopt Mia and Noah who have Down syndrome. That affected our family a lot. It's been pretty neat to see the effect that they've had on our immediate family and on our friends. We actually have a niece who has Down syndrome as well. Our family has a lot of experience with kids with special needs. It's been really neat to see the other cousins and how they interact with them, the way they treat them. Their acceptance outside of our home, I think, is very neat to see, in our oldest daughters especially. They're old enough to understand a little bit more than our youngest kids. I think every parent hopes to teach their kids acceptance of other people, no matter the circumstances. It has been pretty easy for us to teach them that. We have friends who have also decided to adopt kids with special needs through knowing who Brie and Mia are. The relationships are countless that we've formed because of these children. It's almost hard to know what their impact has been because of all those relationships that we've formed and that we've had and continue to have with friends because of this diagnosis. It's been a wonderful journey. I feel like most of the time, we're just on it for the ride as parents, that we're here to enjoy where they take us.

Kecia: I feel the same way. I sometimes wonder what my family would look like or feel like if I didn't have the aspect of special needs, and it would just take away so much of what makes our family who we are. So many of the lessons that you hope you teach your children are being taught by their siblings better than we could have ever hoped. It's really just like we said with Brie when she was born, we would have never guessed that we would choose Down syndrome again and again. When at that point, we were almost praying that they were wrong, that this diagnosis was not right. We looked at her and thought that she didn't look that different so maybe the tests will come back wrong. We were almost hoping for that. It's hard to say that now, to look back and think that you had those thoughts, because I wouldn't trade it because of what it's brought to our family and to our lives. Our lives are richer by having those different needs in our family.

Gerald: I'm going to give you the last word. What advice would you give to a couple who finds themselves pregnant with a child with Down syndrome or who subsequently found out after birth? What would you want to tell them?

Kecia: I'd want to hug them and tell them that they have no idea what a wonderful experience they are about to embark on, and that doesn't mean that there are not going to be challenges, but I would congratulate them and hope that they would see that it's a good thing, that it's a blessing, and that their lives are going to be better because of this new path.

Kris: In our old neighborhood, there was a little boy who had Down syndrome who we knew before Brie was born. We were good friends with their family. He was probably about 16 years old or so when Brie was born. After Brie came home, they came over to visit us one day, and the mom and dad had brought one of their oldest daughters, who was probably in her early 20s, and when they walked in, she immediately turned to her mom and said, "So are you going to tell them? Or do you want me to tell them how lucky they are?" At the time, we didn't understand it, but now I think we do. We understand how lucky we were that Brie came into our lives.