

Orange Socks Story: Kim- CHARGE syndrome
Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I am grateful that Kim wanted to do an Orange Socks interview about her daughter Jackie who has CHARGE syndrome. We spoke on the phone. I really appreciated her candor in talking about the challenges Jackie, who is now 19 months old, has faced, including six surgeries and more to come. Kim counts herself blessed to have Jackie in her family.

Gerald: Kim, thank you so very much for taking the time to have this interview with me to talk a little bit about your daughter Jackie. When did you find out that she had CHARGE syndrome?

Kim: At about 18 weeks gestation, we found out at that ultrasound. Typically, you find out the gender at that point, but we found out much more. They saw that she had what they thought was a cleft lip and something wrong with her heart. They referred us to a high-risk OB who we saw the next week. We had another ultrasound that confirmed that she had a heart defect and a cleft lip, so we were to the cardiology department at the children's hospital. We saw them soon after, and they did an echo of her heart to confirm the heart defect, and told us that was a complete AV canal defect. For the rest of the pregnancy, which was quite a few months, she had lots of appointments with echoes to make sure her heart was healthy and that she was healthy and that she wasn't going to die in utero. They kept a really close eye on her, so we actually did not find out about the CHARGE syndrome until after she was born. We did know about the cleft lip and heart defect. They explained that the heart defect was something that could be surgically repaired, but that she would need open-heart surgery within the first five or six months of her life.

Gerald: Did she have heart surgery within the first six months?

Kim: She was monitored very closely by cardiology and had the heart surgery at eight months. She was born in the children's hospital as they have a fetal health center where they deliver high-risk babies. She spent six weeks in the NICU and really, immediately after she was born, they suspected CHARGE syndrome, so they ordered a lot of tests. They ordered an exam of her eyes and ultrasound of her brain plus hearing tests, all of which were common problems in CHARGE. We had never heard of CHARGE before; I'm a nurse myself and had never heard of it, so I didn't really have any idea why they were testing these things. Within the first few days after she was born, we learned that she had optic nerve lipoma in both eyes, and they told us she could be completely blind. She was profoundly deaf in one of her ears and had mild hearing loss on the other side. In addition to the heart defect and the cleft lip, she also had a cleft palate. Soon after that, they learned she had hip dysplasia on her right side; we're not sure if that is related to the CHARGE or if that is kind of icing on the cake, but it felt like there were lots of hits back to back.

Gerald: Wow, what have been some of the hardest things to deal with or some of the issues relative to her diagnosis?

Kim: Obviously it was hard to digest all of that information at one time. She has the vision impairment, and they couldn't tell us exactly how severe that could be, that it would just take time to see how she develops. We're trying to digest that, then next someone comes in and tells us that she's deaf and partially deaf. It was very, very difficult to digest all of that. We have an older son who was 22 months when she was born, so not even two years apart. As a parent, you teach your kids how to sing with them and dance with them, and we were just trying to figure out how we were going to help her learn to do everything she needs to do with all of these impairments. It was just hard to wrap your brain around all of it. Also, in her first six weeks while she was in the NICU, Jackie had a lot of feeding tubes. They believed at that time that it was due mainly to her heart as she was breathing very quickly and was not able to get the breath to swallow. With her cleft lip and palate, that was also a challenge, so she was not able to breast feed. I was pumping milk and giving it to her. We would try a bottle but she could take very little because of the breathing issues, so she had to have an NG tube through her nose that fed her. At three weeks old, we were fighting this and fighting that, and she wasn't really getting any better, so that's when she had her first surgery, which was the placement of her feeding tube. She still has that, but fortunately has done really well. We've gotten through a lot of these major surgeries and continued to try feeding. Even when she only takes one or two bites or outright refuses everything, we continue to try, and I'm happy to say that she's eating really well now, better and better every day, and she seems very eager to eat. We've avoided oral aversion, which a lot of these kids develop, and I am very hopeful we can get rid of the tube someday. Liquids are still the biggest challenge because they are thin and harder to swallow, but we are working with a feeding therapist and working on it all the time to get her stronger and to make that easier.

Gerald: I'm just curious, do you thicken the liquid at all?

Kim: We do. She had one swallow study that showed she was aspirating on thin liquids, so she was getting nectar liquids at the time.

Gerald: Okay, great; anything else you want to add?

Kim: I will add one last thing.

Gerald: Do it. This is your interview and you're the star, so you have it however you want.

Kim: When the genetics staff originally came in, and told us that they suspected CHARGE syndrome, and ordered all of these additional tests, they basically handed us a book that said CHARGE syndrome that showed several kids of varying ages and different facial features and things common in CHARGE. I think the book literally

said, "This is CHARGE." It took three months to get her genetics testing back, but they said they were suspecting it and told us not to go look on the internet because we'd just freak ourselves out, so of course that's the first thing you want to do, and you do freak out because it is very intense and extreme. There are varying degrees of all of the impairments that she has, the hearing impairment and the vision impairment. These kids are all unique, and you just don't know where your child is going to fall on the spectrum, so it is scary. I didn't know anything about it other than this pamphlet. We just had to wait and see how she develops and what problems she has.

Gerald: So it sounds like you didn't get a lot of comfort from the medical people.

Kim: No, before she left the NICU, we had a provider conference with all of the providers with her cardiologist and audiologist and ophthalmologist, just everybody all in one room. I felt like I had all of this information kind of thrown at me and was trying to digest it as a new post-partum mom who just had a baby a couple of days ago. I felt like they were throwing this information at me but not supporting me or comforting me and telling me that it was going to be okay. I don't know that they knew what to say or how it would be, so it was just more silence than comfort.

Gerald: What have been some of the joys?

Kim: The joys have been a lot. Honestly, it was very hard in those early days. She's about 19 months old now and is getting past a lot of acceptance of the challenges she is going to face and the challenges we are going to face as a family, and just kind of figuring out what we have to do. Lets see what we can do to make her the best she can be. Seeing how she is now is just amazing. You would never look at her and think she has had to deal with all of these challenges. She is happy and sweet and funny, and her personality is starting to come out. She is communicating really well, and her vision and hearing are better than anticipated. Her ability to learn and understand things is better than we could have fathomed, so she's brought lots of joy.

Gerald: That's wonderful. What impact has she had on your family, on you and your husband or older sibling, as well as your extended family?

Kim: She's had a huge impact. It was hard to struggle with the older son at first, trying to figure out how I can give him all of the attention he needs as he was only 22 months old when she was born, and then do everything she needed. He has been very accepting and very understanding, and we've had lots of family support from my in-laws. They live pretty close, and they are here all the time, helping with whatever Jackie needs. The times we have to be in the hospital, They help with Wes while he's at home. My mom lives out of state, but she's just as supportive, and my brother lives down the street. People have been amazingly accepting and willing to help, doing everything they can to help. The neighbors drop things off and send

prayers and well wishes all the time. She has had such an impact on so many people around us.

Gerald: Oh, that's great. If I were to come to you just recently having heard news that I had a child with CHARGE syndrome and I was seeking advice, what advice or counsel would you give me?

Kim: It's going to take time to accept everything you are facing because it is very hard, and there is no sugar-coating it. It is very, very challenging for everybody involved, but hang in there and treat your child as you would any other child. Continue to lead and sing and do all of the things you would with any typical child, and know that they are going to know who you are and learn things around them, and probably do much better than the doctors told you and you anticipated. No matter what happens, you're going to be amazed by them. We are amazed by Jackie every single day, the things she can do and the fight that she has. Just hang in there because it does get better, and it will change your life for the better. In the end, it really is a huge blessing to our family, and we wouldn't change it at all.

Gerald: So despite all of the challenges that you've gone through, the difficult times, the surgeries, etc., it is interesting that you would say that you wouldn't change it; that's wonderful.

Kim: It's been hard to get to that point, but seriously, she has been such a huge blessing to our family.

Gerald: That's great. What's your greatest fear as a parent of a child with a disability?

Kim: That she won't make it through one of these surgeries. She's 19 months old and has had six very serious surgeries. I follow a CHARGE group on Facebook and have a lot of people that I've connected with through social media who have CHARGE children, and some of them don't make it and have a really hard time. The odds of their getting to five years old are way lower than the average population, so that's terrifying as a parent. Every time you hand her over, you're scared that something could go wrong, complications or that she has a hard time with the anesthesia. It's very scary to just let her go and trust that they are going to do their best to keep her safe.

Gerald: I appreciate your sharing that. Any last words?

Kim: Honestly, it has been a really big blessing, and it has changed the way we view the world around us. It has put a positive light on everything and makes you realize what matters and what doesn't, to let the silly little things go because life is very precious.

Gerald: That's terrific. Thank you so much for taking the time to talk with me. I really appreciate it.

Kim: Yes, thank you.