An Orange Socks Story – Kimberly and Bobby: VACTERL or VATER Association

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was really excited to meet with Kimberly and Bobby for an Orange Socks interview about their daughter, Kyla, who has VATER association. Previously, Kimberly and Bobby were pregnant with a child who was diagnosed with Trisomy 13 in utero, and sadly, that child was stillborn. Because of that experience, genetic testing accompanied the subsequent pregnancy with Kyla, and she tested normal. They did not find out until a few months after she was born, that Kyla had VATER association. Kyla is an absolutely delightful child, who had to give me a hug when I left their home.

Gerald: Kimberly, tell me about Kyla.

Kimberly: Kyla is our youngest of four daughters. She is two-and-a-half years old, and she has VATER association. For her, VATER has presented with several different complexities, and it is typically not the same for any two kids. Hers includes back anomalies, ribs and kidney anomalies, a perforated anus and scoliosis. We learned about her diagnosis after she was born. When she was an infant, we noticed right away that something was not typical like our other two daughters. During the pregnancy, we had basic testing done on her to see if there were any chromosomal issues. Our first daughter had Trisomy 13, diagnosed at 18 weeks gestation, when we went in to find out if we were having a boy or a girl. We learned very quickly that she had several different markers that indicated that she had Trisomy 13. Because we had already had a daughter who had chromosome issues, we knew that our chances of having another child with complexities was much higher. That probably led us to make the decision to have some initial testing for Kyla. Nothing showed up abnormal in any of her testing. It appeared that she was fine, which is pretty remarkable considering she is missing a kidney, and she has two on one side that are actually connected as one. Nonetheless, she was born and was healthy, and her doctors didn’t notice anything abnormal. She was jaundiced and basic things that could happen during delivery. We started to notice that she was different pretty quickly. She was very crooked, and she had trouble having normal bowel movements. So, we found ourselves in the doctor’s office very frequently, asking if there was anything we should be concerned about. “What’s wrong? She looks crooked. Something’s not quite right.” Having older daughters, we knew what to look for, so we had her at a chiropractor when she was three months old. She was going several times a week as we were really trying to do whatever we could to make her comfortable because it was clear that she was not comfortable. At about six or seven months old, Bobby actually discovered that she didn’t have a complete anus. With that condition, she was diagnosed pretty rapidly with VATER association, as that’s an indicator. We had an MRI done, which is when they noticed that she had a tethered spinal cord, which is closely associated with spina bifida. It’s on the inside of the spinal cord, and they began to realize the complexity of her ribs and her vertebra, and the severity of the scoliosis that she had. They obviously noticed at that point that she was missing a kidney, and that she had two on the opposite side, so that began our story.

Gerald: So, Bobby, what were your thoughts?

Bobby: It’s pretty simple in that we were able to attack it now that we knew something, but really my thoughts were of anger at the doctors who didn’t notice anything. I was pretty mad, but we couldn’t do anything because we didn’t want to waste our resources on chasing the past. We needed to get her better, so we bore down and took care of it. We saw every specialist we could, as fast as we could, to make sure we got the heart checked out because that was the most important organ. And thankfully, her heart was fine and working perfectly according to our doctors. We were a little bit worried because we wondered if they really know since we just spent seven months with nobody knowing anything, and even saying they were specialists at it, yet they didn’t notice she had scoliosis, and it was severe, so it was hard to trust. At the same time, we kind of just let it go, knowing that we had the best specialists now working with us at the hospital.

Gerald: Kimberly, what’s been the hardest part of this?

Kimberly: That’s a tough question to answer for us. We’ve been so blessed with a daughter who is a fighter. All she knows is going to doctors, going to specialists and being in the hospital. For her, this is a normal part of her life. What I would expect to be the hardest part would be having to explain to her why she has to be in the hospital all the time, why she is pain, why she has rods coming out of her back, why can’t she jump around like her sisters, and all these things that I thought would be the hardest part. The anticipation of all these things never came to fruition, so I guess the hardest part has actually been accepting that I don’t know what is going to come and trusting a doctor to take your daughter when you’re new to the situation and you have a seven-month-old who has to have an MRI, and they are going to put her to sleep. At that point, a parent has fear because you don’t want your infant to be put under anesthesia. Fast-forward to now, and she has had multiple surgeries, and now has prosthetics installed. It’s amazing how the same fear we had by giving over our baby to an MRI, exists today when we give her over for prosthetic installation.

Gerald: What have been some of the hard parts for you, Bobby?

Bobby: I think the hardest is when I see her scars and think back to all she has gone through. When you go through the hardest part, you kind of block it out until you have the memory while looking at something like a scar on her back. She walks around and is super happy, she is the happiest kid ever. Then you see her with her shirt off, and you see her running around, and you realize that she’s got a back that is all cut up. It’s devastating because she is so tiny and so loving, and then you remember that you were really sad or really worried seeing her come out of anesthesia and seeing if she’d be okay. For me, it’s the pain, but it’s crazy because at the same time, I know that she has had this the whole time she’s been alive, so you have to remember that she doesn’t have anything to judge it by. She doesn’t know what it’s like to not go through surgeries or go through what she’s going through. She’s never been like her sisters, she’s only been Kyla. She will adapt and be just fine. We’re the ones who have a hard time adapting. It’s the parents who have a hard time adapting, not the kids.

Gerald: Let me ask you another question, a different one, what are the joys?

Bobby: In between surgeries right now, it’s like a countdown for the next surgery, so the joy is right now in enjoying every moment we can with her while she’s not in pain and is running around. We got her a little puppy, and she is super happy. Every time I see her happy, I’m ecstatic, which is all the time because she is always happy.

Gerald: Kimberly, what have been your joys?

Kimberly: That’s an easier question because Kyla is truly the happiest kid I’ve ever met. She never lets anything hold her back, and we’ve never tried to hold her back. We’ve never tried to explain to her that she will be different than anybody else, and through that, she has flourished. The joy of being a mother is heightened because she embraces us so much. She loves us, she takes care of us, she comforts us, and she’s the one who gets us through the hard parts. When all of these things make me fearful, she helps me through that, and that’s joyful to me. She loves her doctors, she loves the hospital, she loves to play, she loves to read, and she truly is the happiest kid. Again, the joy is just being a mom. That’s the greatest joy. Being able to go through this with her and seeing that all the fears that we had have never actually manifested into anything is a joy. As a typical person, I remember saying, “Why me? Why me? Why me?” When the littlest thing would happen to me, and I learned something along the way. Somewhere it popped in my head as I was watching her one day, instead of “Why me?” it was, “Why not me? Why not our family?” She acts as if there is nothing wrong with her, and that is the joy, to watch her go through everything and come out smiling and happy every day.

Gerald: If I came to you because I had just received a diagnosis of VATER for my child, what advice would you give me?

Kimberly: I think the first thing I would say is that it’s going to be okay. Your life will change, but it’s not going to be so dramatic that you can’t get through it. You take it one day at a time, one specialist at a time, one diagnosis at a time. This type of condition has all different ways that it can manifest, so you may have seven or eight specialists, or you may be in a community of other kids with the same association, and they’re going through something completely different than you. There might be times where you feel like you’re the only one who’s dealing with this particular collection of complexities. Just take them one at a time, because you can tackle all of them, and in my mind, everything is treatable. It doesn't always have the best outcome, but all we can do is treat it and hope for the best, so we do what we can, one day at a time.

Gerald: Bobby, I'm curious as to what you think the impact has been on your immediate family.

Bobby: Being able to notice the little things that make us happy I think. If you don't go through something like this and your kids are perfect, then you're probably not going to smell the roses. I know that is a broadly used thing that everybody uses, "Stop and smell the roses." But you really don't grasp it until you go realize it could be way worse. We could have rods in her back all night long. Imagine laying on rods on your back every day, and you can't get them out. I mean, I get uncomfortable if my pillow is wrinkled on my face, it's pathetic. This little girl never whines about big old rods only on one side of her back, so it's not even. Imagine always being tipped over with a metal rod going down one side of your back. Everyone has slept on a pull-out at one time, so you know how uncomfortable the dang bar is on a pull-out bed or a couch, and she lives with it and says nothing about it. It really has brought joy to our family to make us understand that there is nothing that is too hard to get through.

Gerald: Kimberly, I'm going to let you have the last word. Anything in conclusion you'd like to say?

Kimberly: Being given a diagnosis is obviously not something any parent ever wants to have happen or expects to happen or knows how they will deal with it until it does happen. The families we come in contact with who have all sorts of different complexities have this resilience about them. I don't think it is something that you develop after the diagnosis, I think it is something that is always within you, the strength that's within you. This resiliency is there and just untapped, and you can get through anything. It is not something where you want to look at someone else and think, "Wow, you are so strong, I would not be able to deal with it or how do you deal with that?" We get that often, "How do you deal with a surgery or a follow-up or when your next appointment is to schedule the next surgery? I couldn't deal with that." The reality is that you could. We all can do what we want, and no, it is no fun. It isn't easy, but you do it, and it doesn't impact your life in such a way that it changes who you are. You figure it out, you work together, you get your friends together, and you get your family and your community and anybody who can help, you who wants to be a part of your process. You grow in what really matters, which is loving and supporting each other. They help you through the surgeries, the recoveries and the doctors' appointments, watching other kids while you're doing it. You'd think you'd get exhausted, but you don't. You have times where you get tired, but the reward is in their little faces. It's in the love that you have with your kids, the ones who are going through it and their siblings. They are learning all about love and about what really matters right in their family units, and that's something that we wouldn't trade.