# An Orange Socks Story- Alyssa: Prader-Willi Syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I appreciate Alyssa having an Orange Socks interview by phone with me about her daughter, Kimber, who has Prader-Willi syndrome.

Gerald: Alyssa, thank you so much for speaking with me. I'm excited to learn your story. When did you find out that Kimber had Prader-Willi?

Alyssa: Kimber was actually born premature, and that is not typical of Prader-Willi syndrome. She was born about two months early, and right away it was pretty apparent that something was wrong. She was much smaller than they had estimated on ultrasound. She was very limp, and she slept 24 hours a day, seven days a week. They could take blood, give her shots and give her baths, and she'd sleep through the whole thing. For the first week, my pediatrician said that since it was a traumatic birth, let's just kind of let her rest and see if she pulls out of this. At about day seven, he said that this is weird, and we need to send you off to another hospital. Two months later, we were discharged from the NICU. We didn't have very many answers. In fact, they told us they didn't expect Kimber to live past six months just based on the symptoms she was showing and her low muscle tone. She was just completely a rag doll. We were sent home with a G-tube, and we had a couple of tests out there waiting for answers. We had been home for a couple of weeks when the geneticist called and told me that Kimber had Prader-Willi syndrome. That was sad, but it was kind of happy for us when we were told that she wouldn't live past six months, and now we are told that she is going to live a pretty average life span. There would be some challenges, but we got to have our little girl, so I think that softened the blow of the diagnosis a little bit.

Gerald: What have been some of the hard things in caring for Kimber?

Alyssa: It's hard to watch her work twice as hard to do something that comes so easily to a normal kid. On the one hand, I'm proud of her for being so sweetly stubborn and determined to do what she does. Complications with the syndrome include some food issues, because kids with Prader-Willi syndrome don't have the connection between their brain and their stomach to tell them when they're full, so Kimber thinks she is hungry all the time. We lock our fridge, and we have very strong dietary guidelines. She is on a very strict medical diet, she eats at certain times, and we don't eat any other time of the day. That's kind of difficult for a lot of people who come to our house and get used to those different kind of structures.

Gerald: What are some of the joys that Kimber has brought with her?

Alyssa: Oh, man, that's going to make me cry, because when we got the diagnosis, we were told that Kimber's life was going to be very hard and very challenging, and that basically she was going to be a burden on her family and that we needed to prepare ourselves for it. They couldn't have been more wrong, because Kimber is just absolutely hilarious. We were told that she wouldn't show much emotion and that she would struggle to talk and walk and do a bunch of things that typical kids do. She has the vocabulary of an adult and uses it very well, and she gets all of us laughing so hard. She is also incredibly sweet and so concerned about others' needs. She's just a sweetheart and so much fun, and I can't imagine our lives without Kimber.

Gerald: I should have asked this previously -- do you have other children?

Alyssa: Yes, Kimber was our first, and we have an 18-month-old little boy named Brady. I think that having Kimber as the first child was kind of a rough way to start, because it was very intense, but in the same sense, we didn't know any different. We didn't know what it was like to have a kid who doesn't have 4-5 therapies in a week. It was just normal for us to feed a baby through a feeding tube, we didn't know anything different. When we had Brady, that was huge. It was a shock for me to go through a second mourning period because I didn't know what was coming. To see Brady easily eat a meal and roll over and do stuff like that was a different experience. I think that if I had that previously, it might have been harder to watch Kimber struggle so much. It has been interesting having the two, but he pushes her, and she wants to be the big sister. So, having Brady has been the best thing for her because she is so determined to be the big sister and do everything that Brady does and do it better, and it's funny to watch them.

Gerald: That's great. What has been the impact of Kimber's life on the rest of your family, your immediate family, your friends and your neighbors? How has she affected them?

Alyssa: We were very fortunate in that we talked to other families across the nation and across the world, and a lot of times, it seems they struggle getting friends and family to understand the limitations with Kimber's syndrome, particularly the dietary restrictions. We live in a society where if you love a kid and you want to show a kid that you love them, you give them a piece of candy. It's different for our family, because how do you do Halloween if you don't do candy? It's little stuff like that that I'd never thought of before, and all of a sudden, I was stressing over it with Kimber. Our community has really rallied around her, and at Halloween, everybody has some non-edible things for Kimber. We've had the opportunity to speak to different schools. There's a university close by, and we are able to go up there on a fairly regular basis and speak to the students there who are going into special education. They get the chance to meet Kimber, talk to her and see what it's like to live with the challenges of having a child with a disability. We've also been able to talk to the middle schools and other schools. Their science classes usually invite us in when there's a genetic chapter, and we get to talk to them about Kimber. I've had so many parents come up to me later in the grocery store and say, "Are you Kimber's mom? My student so and so says they absolutely loved your presentation, and they want to go into special education now, and they want to work with kids with special needs." I love that she's been able to be an advocate, not only for kids with Prader-Willi syndrome, but for kids with special needs, because in our society, people have a certain image in their minds of what a kid with a disorder is going to look like and act like. Kimber just blows all those stigmas out of the water. She's just incredible. We've had so much support from family and friends, and people are always asking how they can make it safer for Kimber when we go over for barbeques. I get texts asking how they can make this so that Kimber is comfortable, and what kind of food should they be serving so that Kimber is safe. We've been very fortunate.

Gerald: And she's four years old.

Alyssa: She is.

Gerald: So, nothing that you were told has come about. She is completely different than what was predicted by the medical establishment for her. That is wonderful, and what a wonderful story and great service that you're providing to educate the community. I think that's terrific. If I were to come to you just having received the diagnosis that my child has Prader-Willi, what advice would you give me?

Alyssa: Oh, that's a good question. I look at pictures of myself during the process when we were trying to get a diagnosis, and we have video clips, and sometimes I just want to reach through the screen and tell myself to hang on, it's going to be okay. I would just say not to stop dreaming for your kids. The hardest thing was people telling me all the things that she wouldn't do, that she couldn't do, and we chose to just push Kimber until she showed us that she couldn't do something. We expect her to do it, and every single time, she has risen to the occasion. She has her own goals and her own grades, and we are going to help her find a way to accomplish those. These kids are just incredible, they are so determined, and if you don't limit them, they are not going to limit themselves. I would just tell the new parent to hang in there. The first year is hard while you're learning all about the special-needs community, and all of the different services and acronyms and all of that, but it's an incredible little journey that we are on. She has taught us so much about what it's like to really love deeply and unconditionally, and what it means to endure to the end and fight for what you want and for what you love.

Gerald: Great advice, wonderful advice. Any final thoughts?

Alyssa: I don't think so. I think the important thing to remember is that any kid with any disability is just a kid. They just want to be loved, they want to be a part of everything and they don't see the limitations. As parents, we need to help them accomplish what they want to, there's no reason to treat them any differently than any other kid.

Gerald: That’s wonderful. Alyssa, thank you for taking the time to speak with me about Kimber. What an honor to meet you by phone, thank you for sharing your story.

Alyssa: Thank you for giving me the opportunity.