An Orange Socks Story – Shirell and Danny: Prader-Willi

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I am so glad that Danny and Shirell sat down with me for an Orange Socks interview about their son Sam, who has Prader-Willis syndrome. When did you notice that there was something wrong with your son?

Shirell: I knew there was something off when he was born. I knew there was something different. He was very floppy; they had to pull him out with forceps. He was a C-section baby, and it was just kind of unique that they had to use forceps to pull him out because he was pretty lifeless. The doctors noticed that there were some different things going on. but I did not. To me, he was a perfect baby, but he did have distinct eye features, and his hands were clenched, and his little legs came out kind of floppy, like a little frog. He also had undescended testicles, which was kind of a red flag to the doctors.

Gerald: What was your reaction to this?

Danny: I knew within seconds that there was something seriously wrong with him. He just wasn't thriving. Like Shirell said, he was limp and kind of out of it. It looked like he was not going to survive, honestly. But, he did, and he did well after the first year and a half.

Gerald: What have been some of the challenges? What have been some of the hardest parts?

Danny: Just dealing with his insatiable appetite and keeping things locked up, plus his inability to use the restroom. Last night he had a couple of bowel movements that weren't much fun to deal with for both of us. Sometimes he gets really frustrated. You can imagine, like any15-year-old boy, he gets frustrated as it is, but he can't express what it is that's bugging him. The frustrations are probably small in comparison to the rewards that he brings into our family.

Gerald: What are the hard parts for your, Shirell?

Shirell: There are different phases. When he was younger, it was the not knowing if he was even going to still be with us because we had several incidents where he had to be taken to the hospital by ambulance or life flight. That was hard because it played on our emotional well-being all the time. It was days and months of him not doing well. We didn't know if he was even going to survive. Early on, that was a hardship as well as not making his milestones when he should have, like talking, walking, crawling and eating the way he should. All of those were delayed, and now he's pretty much still non-verbal, and that's hard to see as a mom. You want him to progress and do well. Now it's hard because he's a teenager, and with the hormones and who knows what else is going on in his body, he can be aggressive. He isn't intentionally mean, he won't hit you or anything like that, but he will just have these out-of-control behaviors when he's frustrated with different things, so that's tough.

Gerald: Tell me about the joys.

Shirell: There are a lot of joys. Sam just has that fun little smile that he puts on his face, and there's not a smile like his. He's got crazy crooked teeth, and he can drool like no other. I guess only a mom and dad can love that face the way we love him, but once he has that smile on his face, it just makes everything okay. He can make a really hard day better. Just by his giving you a hug or sitting by you, he's got a soothing affect. He has a sweet spirit.

Danny: He's a special boy. He's here in our family for a reason that we haven't totally figured out yet, but I think we've got a few insights to it. Like we mentioned, he has been a blessing to his sisters and a blessing to us. At time he has driven a wedge in our marriage, and at other times, he has been a healing salve to our marriage.

Gerald: How about your extended family? What kind of impact has he had?

Shirell: I think everyone adores Sam. They may not always understand what Sam's going through or the full impact of his condition. We get together for family dinners and so forth. Much of Prader-Willi is about the food. If you think about a family gathering or any kind of party, there's always food. That's a big part of the deal. That part has always been hard because I think grandparents and aunts and unclesthink, “Just give him the food.” But you can't always give him the food, or he could be in serious trouble.

Gerald: If I were to come to you and having just found out that my child had Prader-Willi, what advice would you give me?

Danny: Hang in there and contact the local support group. Don't read a bunch of negative stuff on the internet. Each case is unique. We’ve seen other children who are either on the high end of functioning or the low end of functioning where Sam is. Some drive their parents crazy just talking; we don't have that issue. Most of them have that innocent loving spirit about them, which we have really enjoyed.

Gerald: What advice would you give me?

Shirell: Just know that the joys will outweigh the hardships. That everything will be okay. If you are a mother and a father, I think hopefully that instinct of love will just kick in. They will show you unconditional love and just a lot of joy. They focus on the simple things of life, and I think we could all learn a lesson in that. We love our boy. He's a sweetheart. There were days early on where I honestly said the pity thing, "Why me? Why? Why? What am I supposed to be learning? Why?" And now there are a lot of days when you feel that joy and I think, "Why? Why me? Why do I get to experience this? This is amazing! Why am I so lucky to be your mom?" A lot of nights before I put him to bed, I say, "Why am I so lucky to be your mom, Sam?"