An Orange Socks Story – Beth and Bryce: Angelman syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: It was my privilege to have an Orange Socks interview with Beth and Bryce, the parents of Smith, who has Angelman syndrome. Beth, will you please tell me about your son, Smith?

Beth: He was diagnosed with Angelman syndrome when he was two and a half, almost three. He was born with Angelman syndrome, which we didn't know at the time. But he's missing a marker on his 15th chromosome, and sometimes it can be a mutation and sometimes it can be a complete deletion of that marker. His is a complete deletion. Usually kids with a complete deletion are a little more severe than kids with the mutation. We went to an Angelman syndrome conference a couple of summers ago, and noticed a wide range of abilities among the kids, from not talking, walking or using their hands, which is our son, to walking and even saying a few words, or they can feed themselves. Our son can't walk, and he can't talk. We feed him every meal. He can roll around, and he can sit up.

Gerald: How did you find out about the diagnosis?

Beth: After he was born, I noticed he wasn't looking at me at all. At around four to six weeks, he still wasn't looking at me. We thought maybe it was his eyes, so we got his eyes checked out, and they were fine. There were just more developmental issues as he got older. He wasn't rolling, he wasn't crawling, he wasn't using his hands, he wasn't cooing, he wasn't talking, he wasn't looking at things. So, by the time he was one, we started the fun cycle of neurologists, geneticists, specialists and GI specialists, all trying to figure out what he had.

Gerald: So, Bryce, how did you feel when you got that diagnosis?

Bryce: We were elated, because it had been over two years and finally a microarray analysis of his blood was able to determine what he had. We were excited because prior to that, some doctors were thinking maybe we could test for muscular dystrophy, and if that’s the case, then he may only have a short time to live. When we found out it was Angelman, we were really excited because he'd be able to be with us until we kicked the bucket, and that was really exciting for us. Therefore, we could try to make a plan, try to figure things out a little instead of just being in the dark for so long. Yeah, that was an exciting day.

Gerald: So, you knew something was wrong, you just didn't know what it was?

Bryce: Right, yeah. He was a medical mystery for two years.

Gerald: So, what's been the hardest part of this?

Beth: Our second son, who is neurotypical, can do everything. We would watch families with their neurotypical children walking down the street, doing just completely everyday normal things, and that wasn't our normal life. Like Bryce said, thinking about not being able to take him hiking or fishing was kind of a different way of defining a child’s relationship with a parent. The hardest thing was kind of just this loss of a dream of having this child who’s going to be walking and talking and laughing. Well, he laughs, but we don’t have that relationship. We understand now that it’s a different kind of relationship, but then it was hard for me to go to playgroups with other moms when they all had these kids who were whining to them and wanting things. I thought it was so cute because my son pretty much just laid there and didn't do anything, and they would complain, "Oh, it’s so annoying when my son does this." And I would think, "Oh, that would be the best thing ever!" I kind of felt a little left out of normal mom raising.

Bryce: He's our first, so I had these dreams of walking and playing. I'm a big athlete, and my dad taught me to throw a baseball, and I played all of these sports, and we'd go hiking, fishing, whatever. Then the realization hits that this is going to be your whole life, and you will probably have to change his diapers your whole life and feed him your whole life. It made me realize perhaps how selfish I was to think that at a certain level, I was going to have to be a caretaker if you will or a nurse or whatever you want to call it, and I don't get paid for this. And you don't get the interaction, you don't get the, "I love you, dad." That, for me, was the hardest. I was a young dad when he was born, and I'm still very physically fit. I wanted to teach him how to read and write, all those types of things. Then it turned into, well, if he eats the food today and if we can actually get him to go to the bathroom, that is exciting. When he has a good bowel movement, we are thrilled because we know he's going to be happier and he's going to sleep better. We know he's at peace, and that's turned into our joy in a way, seeing him at peace, seeing him be comfortable. It was praying, thinking, reading, studying and asking people for help, which was something new. Neither of our parents had had any handicapped kids, so it wasn't like, "Oh, mom knows what this is like, so maybe we could ask her." Instead you feel alone on a lot of levels. That was, for me, just emotionally and mentally more challenging. I don't really mind doing the diaper stuff and feeding him because he kind of likes it. You have no idea if he's feeling sick or sad as he doesn't communicate with you, so you're just in the dark a lot. That can be a really sad thing.

Gerald: So, Beth, what are the joys?

Beth: I would say he has a happy demeanor, and kids with Angelman syndrome are known to have kind of an angelic demeanor about them. I think it brings me a lot of joy when he smiles and when he's happy. Also, having another child to experience Smith, now that he has a sibling, we can say, "This is your brother." They hold hands, and I think he's still a part of our family. I feel like when he was first born, you would hear people who had special needs children say, "I wouldn't change my son for anything." I was feeling so selfish because I thought, "I would! If I had the power or ability to change him, I would." So then, as the years have gone by, and we've gotten to know Smith on a different level, there's a different relationship you have with someone that can't talk. Now that we know Smith on this dimension of communication, I feel like now I've gotten to that point of understanding what those parents meant by, "I wouldn't change him for anything." Because what he's brought to us, and the understanding and enlightenment I've had from having a special needs child, is a way bigger education than I ever could have hoped for or dreamed of. I am so grateful for it. It's almost an honor for me to change his diapers and sing to him even when he's mad. There's kind of an honor in taking care of someone who can't take care of themselves.

Gerald: So, Bryce, what impact has he had on your family, extended family or even your immediate family? What impact has he had?

Bryce: It's something you don't expect initially. We recently had both families get together and kind of have a celebration for Smith's eighth birthday, and it really was a beautiful experience because we were celebrating Smith. A lot of times it seems like the parents say, "Oh, you're strong people," and "Oh, you're amazing," and "Oh, how do you do this? Or how do you do that?" And we don't think like that. We think Smith's amazing. We want to have a celebration for Smith and see the impact he's had on Beth's family, on my family, on my seven siblings and Beth's four siblings. The tears, the joy, the kids, his aunts and uncles, his cousins, they all see that there's this soul that's in Smith. I love this aspect, that you recognize, obviously he has problems. What's so beautiful is watching the hearts of these kids, or your parents or aunts and uncles who just want to be with him. They want to help. We watch his younger brother wanting to help him, not because we tell him to, but because this five-year-old kid wants to make sure Smith is around, or holding his hand while they're watching a movie together. If Smith weren't around, you would ask yourself certain questions about humanity. "Where is the humanity in this world?" But Smith naturally brings out those beautiful things, in rigid, sometimes stubborn people. And wow, it's powerful. Really powerful.

Gerald: So, Beth, if I came to you because I just found out my child had Angelman's, what advice would you give me? What would you tell me?

Beth: I would probably want to be there to support you mostly. I'd say, "If you ever need someone to talk to, I'm here." I would assure you that your child is going to be a light in your life, just like any child would be. It's going to get harder and easier as they get older, because you're going to be able to communicate more with them as they get older. But as they get bigger, it's going to get harder, just like any child. I think, harder and easier, harder and easier as they get older. I would just admonish you to keep going and keep researching and making sure your kids are healthy and happy, and just be a good mother and father to the kids basically.

Gerald: What advice would you give me, Bryce?

Bryce: I would say it's okay if you feel like you can't do this on your own. I'm here for you, and there's a whole community of people who will help you, who are excited to help. As cheesy as it sounds, you're not alone in this. There are people who want to help. But also, without getting too spiritual, recognize that you have been given this child for a reason. There's a lot of trust that goes into it. You're a beautiful, powerful, amazing human being, and you'll see how great having this experience will make you in a way. You will become someone more caring, loving, willing to reach out and willing to take care of. It almost seems as if Smith has transformed me personally into a more humble, kind, selfless person that I'm so thankful that at least I'm trying to become that. But really, if you stick with it, like Beth said, your heart just gets bigger, and the joy of life really shines through him. It's just a beautiful thing. Cry of course, laugh, have fun. With our neurotypical child, it's a different type of joy. He does the same things on a certain level, but Smith helps you grow in ways that you can't imagine. That's what I'd say.