An Orange Socks Story: Ryann and Chuck- Spina Bifida Myelomeningocele and Hydrocephalus

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: What an honor it was for me to have an Orange Socks interview with Ryann and Chuck and talk about their son, Jayden, who has spina bifida myelomeningocele. Their story is unique because Jayden came to them through the foster care system, and they later chose to adopt him. Ryann and Chuck have blessed Jayden's life by providing him a stable, loving family, and Jayden has blessed their life as you will hear.

Gerald: Chuck and Ryann, thank you so much for taking the time to meet with me to talk about your son, Jayden, who has spina bifida myelomeningocele. His story is very unique in terms of the Orange Socks interviews. You adopted Jayden. Ryann, tell me a little bit about where you met Jayden, and how you came about adopting him, and then I'll talk with Chuck about it, too.

Ryann: We were foster parents, and we got a call about Jayden. They explained his condition, which was spina bifida, and told me that he had two clubbed feet, which is usual with spina bifida, and hydrocephalous. He had been born just two weeks prior to the DCFS call. They said that they had been trying to find homes that would take him, but they couldn't find anyone. My supervisor called us and asked if we could take him. We were a little bit leery because we didn't know much about spina bifida. We told him that we would research spina bifida and get back to them. We looked it up and figured we could probably handle it, not really knowing what it was going to be like. We got him three weeks later after he was released from the hospital, he was five weeks old.

Gerald: So, he was just a baby.

Ryann: He was just a baby, yeah.

Gerald: Okay.

Ryann: He spent two weeks in the hospital, and then he went to a shelter home for three weeks until they found us to take him in.

Gerald: Okay, you decided to adopt him.

Ryann: We decided to adopt him. It was a long process with six months in the foster care system. His mom decided that she wanted to have a better home for him, so she was able to sign her rights over, and then we were able to adopt him through the state.

Gerald: Great, how old was he when you adopted?

Ryann: He was 17 months then.

Gerald: So, he was still very young.

Ryann: He was still under our foster home from age five weeks to seventeen months, then we adopted him legally and he's been ours ever since.

Gerald: Chuck, you came in later.

Chuck: I did, yes.

Gerald: You were not on the scene when Jayden was an infant, but how old was he when you entered the scene?

Chuck: He was two and a half. After we got married, I had fully adopted him as my own.

Gerald: What were your thoughts when you were dating this woman who had a son with spina bifida?

Chuck: It was actually somewhat different. I didn't ever expect to do something like this. I liked the way she treated the children, and he had such an easygoing, outgoing personality that he was easy to like. It was just like a magnet and interesting. She's taking many other classes, and I'm still learning as it comes along, but I like the attitude that he doesn't let anything get him down.

Gerald: He's a great kid. In interacting with him, he is super, top-notch. Ryann, tell me what have been some of the challenges? He's how old now?

Ryann: He is nine now.

Gerald: You've had him essentially nine years minus five weeks, but what have been some of the hard things that you've faced with raising him up to this point?

Ryann: Now that he's older and knowing that he is different from other children, and that he can't do what they can do, he fully wants to and he tries to do what he can. It's hard for me as a mother to see him wanting to do those kinds of things. He would love to have real legs that work, so he comes to me and says, "Mom, how come my legs don't work? I want to be able to run or jump instead of using crutches."

Gerald: Has he had challenges medically?

Ryann: Yes, he has.

Gerald: Okay, tell me a little bit about that.

Ryann: He's catheterized, so that's also hard for him to do stuff because he wants to go to the bathroom like a normal boy. He has had reconstructive bladder surgery so he can be more independent. He is catheterized through his belly button, which to him is normal, but he would like to be able to go to the bathroom normally. We've also had to have several surgeries to correct his clubbed feet, and sometimes it's a 50/50 chance that it will correct them. We've had his tibias rotated so his feet would stay straight. He has hydrocephalus also, so we have a shunt that we have to watch so that the fluid from his brain will drain right, so we've had several surgeries for that.

Gerald: Okay, so Chuck, you don't have anything you found particularly challenging?

Chuck: As he's gotten a little bit older, he's begun to develop a little bit of scoliosis, something else we had to work with. We've pretty much stopped going to physical therapy as I work with him a little bit more one-on-one when I can.

Gerald: Because you are a physical therapist.

Chuck: And that's important.

Gerald: And because you can do those things.

Chuck: I don't do what occupational therapy does. I still don't do a lot of the hand-eye coordination, but I definitely try to work with his sitting straight and doing what he needs to do. We pushed him into getting a walker instead of a wheelchair early on, and then from that into his crutches, and that's made him a lot more independent. I've seen a lot more teenagers that are wheelchair-bound with various conditions, and their demeanor was poor posture and poor attitude, but the ones who were on crutches were stronger and healthier and got around a lot easier. I thought that was a big issue when we met, to get him into something that's more mobile.

Gerald: Sure. Tell me about the joys.

Ryann: The joys?

Gerald: What are the joys?

Ryann: He never gives up. If we want to go hiking, he wants to go hiking. He wants to go up that mountain, and he wants to go down water slides. He wants you to carry him up and then go down the water slides. It doesn't matter how heavy, it's just the excitement he sees. We put him in wheelchair basketball, and he loved that, just seeing that there are other things that he can do in his way and not have to be like the other children. We put him in soccer, so he played soccer with his crutches, and he loved that, too.

Gerald: That's great.

Ryann: And he loves gymnastics. Just trying to get him involved in the community and in sports is a joy because that's what he wants to do; he wants to be just as normal as any other child.

Gerald: Do you have any other joys that you want to add, Chuck?

Chuck: He loves riding ATVs. He loves getting out there and doing what normal kids his age can do. He loves those team sports, but there are a lot of high-risk sports that he enjoys doing with me that maybe his mother doesn't always approve of. He is a typical boy, he likes what nine-year-old boys would like, monster trucks, cars and motorcycles. He loves sporting events like watching the Jets, and that is always fun. He might not be able to participate like other boys, but he still has the same interests and loves.

Gerald: After you adopted him, what impact has his life had on your extended family?

Chuck: I think a lot of adaptation from the family. He has cousins who can run and walk, where Jayden still wears a certain type of diapers or some kind of protective device just in case he has an accident. People understand now that he has certain medications he has to take in the evenings and mornings. They've really taken an interest in learning how to catheterize him and helping him with that. Most of the homes that he goes to where the family members live have some kind of supplies there because they understand. It's interesting to see how the family dynamics have changed. Until Jayden, they had a couple of grandkids and great grandkids who were able to do everything on their own, then Jayden came along, and they were introduced to something that was a little bit more of a challenge. For the most part, most extended family members have taken on the challenges pretty well and were able to work with him and learn as we went along, and it's interesting to see how their drive and determination has helped Jayden be more normal instead of a burden or a type of outcast or something like that. It has been fun to watch, and at least he feels like one of the normal grandkids or cousins when we go to different homes.

Ryann: Jayden has impacted our extended family by helping us understand special needs in more depth. We are more positive and accepting. He has taught us patience, which has enhanced our lives. His love is never ending, and his personality has given us joy, laughter and amazement. We appreciate life as if through the eyes of a child. His joy in accomplishments are, "hoorah," moments for us. He expects nothing and accepts everything. His determination is contagious, something we all needed to incorporate more fully in our lives. When Jayden came into our lives, we knew immediately that he was ours. He was heaven in our arms. He makes us love and appreciate all he does, and his gratitude and appreciation are abundant in our whole family.

Gerald: Well, that's great. Ryann, if I were to come to you just having received a diagnosis in utero or after birth, or in fact even if I wanted to adopt someone with spina bifida, what advice would you give me?

Ryann: Not to be scared. He has brought the greatest joy and love to my life. He teaches me something new every day, and I'm grateful for that. I wasn't scared to take on a child like him because I just told myself that I could do it and it would be okay, and he's blown me away. We were told that he wasn't going to thrive and that he might not make it, but he's proved them all wrong. He has done so much more than we thought he could do.

Gerald: Super. Chuck, do you have anything to add for advice?

Chuck: I'd probably say to look at it a little bit more objectively as well as understand that this isn't something that's going to go away after puberty. That child might live at home until age 18 and might not leave home until after he gets married or finds himself a little bit more independent. Understand more of the mental as well as the physical limitations. Just do your homework on it before you take on a role like that, make sure you're the type of person that can tolerate this long-term. It's something that I'm still learning as we go along. Aside from what Ryann talked about with the physical handicaps, children with spina bifida also have some mental learning disorders. Math is extremely hard along with time, money and the times tables, and his memory retention is pretty short so you have to be patient with that. You have to understand that he might not progress the same as kids in his class, so there's a lot of hands-on that the parents have to do with the teachers and the school districts. You have to find the right schools and the right principals who are going to be willing to work with him with either the cathing or the extra time with education. Understand that his learning capacity or capability may be different than other kids, and he may be always a little bit behind the other kids, but to him that's an improvement from year to year.

Gerald: Ryann, you adopted this little boy. Chuck, you also adopted him a couple of years later. He was five weeks old and wasn't expected to thrive. You have gone through multiple surgeries. You had the hassle of adoption and all the things that went with that. Was it worth it?

Ryann: Yeah, I'd do it again.