Orange Socks Story - Maria and Brandon: Chromosomal Deletion 9Q

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I'm grateful that Maria and Brandon invited me to their home for an Orange Socks interview about their son, Chase, who has chromosomal deletion 9Q. As far as they know, Chase is the only one in the world with this diagnosis, or at least with Chase's severity. Chase is a beautiful, energetic three-year-old, and I was glad I had the chance to meet him.

Gerald: It's an honor for me to meet with both of you to talk about your son, Chase. He has a very rare condition, tell me what his condition is, Maria.

Maria: He's missing part of his ninth chromosome off of the Q branch. Most deletions on the ninth chromosome are on the P branch, so it is rare that his is on the Q branch, and it's also the biggest piece missing that they've found so far. We found some similar ones, but they are often smaller or some of them are inside of his deletion, so they have similarities, but nothing has been the full exact thing as Chase yet.

Gerald: So, he is unique in the world.

Maria: Yep.

Gerald: As far as we know.

Maria: Yep

Gerald: That's awesome. Chromosomal deletion 9Q is the official name for it. When did you find out he had that diagnosis?

Maria: The diagnosis was given 12 days after he was born, but we knew at 14 weeks in utero that something was up. They found his cleft lip at 14 weeks.

Gerald: What advice did you get at that point when you were carrying him?

Maria: We found out about the cleft lip at a place in the mall where we went to find out if it was a boy or a girl just for fun, and they told us he had a cleft lip and told us to get that checked out. I told my doctor, and she sent us for our 20-week ultrasound a little bit early. They found an umbilical abnormality in his cord, so the ultrasound tech suggested that we do some genetic testing. They could only do very limited testing while he was inside except for doing the amniocentesis, which would be risky that early, so we did all of the testing for Down syndrome or Trisomy 18, and that came back with an elevated risk of Down syndrome, but obviously it wasn't that. Once he was born, they did the full blood panel macroarray, I think that is what it's called, and they found that he was missing a good chunk of his seventh chromosome.

Gerald: Interesting so Brandon, what were your thoughts when you found out that you potentially had a child with a disability?

Brandon: I just wanted him to be here as healthy as he could be. I'm not one to dwell on any negatives, just get him here, and I'm going to love him however he comes. To me, it was really irrelevant. Our main concern was that he wasn't going to make it because there was a slight chance that he wouldn't even survive birth. That was probably my greatest fear, but just getting him here was all I cared about.

Gerald: That' great. Maria, what have been some of the hard things that you've had to go through with Chase?

Maria: Probably the hardest is how many things I have to keep track of, like doctors' appointments. Over the course of his life, he has probably had 20 specialists. We were kind of narrowing it down a little bit to 15, but we were at the hospital a lot. He has several appointments each week between hospital therapy and surgeries. He has had 10 surgeries, so it's staying really busy and staying on top of his appointments. He's an easy kid, really low-key, and super lovable, so probably the hard part is just how busy he keeps us.

Gerald: Does he have a tube?

Maria: He's got a G-tube.

Gerald: Ok.

Maria: His cleft was pretty severe when he was born. It's bilateral lip and pallet, and so far, they've fixed his lip and his soft pallet, but his hard pallet is still open. We are starting oil feeds a little bit here and there, but he does a lot better just being tube-fed.

Gerald: Through the G-tube?

Maria: Yes.

Gerald: Brandon, what are some of the joys?

Brandon: Actually, just what you're seeing right now. He's on the carpet and in his world, and he's happy. That's the best thing in the world. He gives hugs, and if he's close to you, he'll just grab hold of you and just hold you really, really tight. I know that's his way of saying, "I love you." It's really just to see him happy when he's in his own little world and smiling and making noises and stuff like that.

Gerald: How about you, Maria, what are some of your joys?

Maria: Same thing. He loves being on the floor. I love holding him, he’s just super loveable. It took him a long time to smile, like probably 8 months, so once he started smiling and doing it consistently, that really brought us a lot of joy. Any time he smiles today, it lights both of us up, because it’s still few and far between, but he’s doing it a lot more regularly now.

Gerald: What impact has he had on your family, his older brother as well as maybe your extended family?

Maria: I remember talking to my dad about it, and especially when Chase was still in utero, he was praying that things would get better and things wouldn’t be as bad as it seemed. At every other appointment, we were finding out heart issues and brain issues, and his auditory and optical nerves are underdeveloped so he’s deaf and blind. And my dad finally realized that he’s supposed to be like that, he’s supposed to come teach us stuff, and that’s all he has been doing. He’s amazing. He teaches us new things every day, like patience and deeper amounts of love. His little brother is 15 months old, and he just crawls all over Chase, he loves him to death, and they are just best friends.

Gerald: That’s great. You have gone through a lot. How many surgeries again?

Maria: Ten.

Gerald: Ten surgeries.

Brandon: And with each surgery, he’s had at least five different procedures.

Gerald: Any others that need to be done yet?

Brandon: Yeah.

Maria: Definitely.

Brandon: They’re starting to become a little more in between, but definitely he’s still got some more that he’ll have to have.

Maria: A lot of cleft work, and then he’ll eventually need some sort of kidney surgery. His right kidney is pretty much shriveled up and decaying, but he’s got his hard pallet to be repaired, and he’s got and under bite, so they’ll have to break his jaw and pull it back.

Gerald: Still a lot of things?

Maria: Yep, a lot of cleft-related things.

Gerald: That's interesting. If I were to come to you having received the same type of diagnosis for a child either in utero or shortly thereafter, what advice would you give me? I'm going to ask both of you, but Brandon, what advice would you give me?

Brandon: Before I answer, I do want to say one thing. One of the things I really enjoyed with him was when his mom was pregnant with his younger brother, she really had trouble sleeping in the bed, so Chase and I slept together every night for probably a good month or two months. I feel like we really bonded from that, because to this day, if he's laying up under me, he crashes. It was an awesome thing to sleep with him. He's a wild sleeper, but it was really awesome to get that bond with him.

Gerald: That's awesome. What other advice would you give?

Brandon: Any advice I would give a parent is that you really can't dwell on the negatives. Take it one day at a time, because with Chase's condition, there was really nothing the doctor could tell us per se of what to expect. You just have to take each day as it is and know that some are going to be great and some are going to be on the down side. Never think of it as a total bad thing. I talk to him like he's normal even though he can't hear. I treat him like he's normal even though he's not, and I want him to feel like he's as normal as he's supposed to be. I'm not going to treat him any differently. Technically he is special, but that's just my son, and that's all he's ever going to be to me regardless of whatever his condition is, you know. You have to dwell on the positive because if not, the negative will eat you alive. In the back of my head, I know there's a chance that I may wake up one day and he might not be here, but I can't keep that at the forefront. When I see him laugh and see him smile in the time I get to spend with him, that's worth more than anything else in the world.

Gerald: That's great. Maria, anything else you want to add?

Maria: One thing he said that stuck out to me that was to take it a day at a time. I used to be a very structured, scheduled person, and even throughout my pregnancy, Chase would not allow me to be. I would think that I had this under control, that I'd come to terms with what we had found out so far, and then something new would pop up. We did not have one ultrasound that went smoothly. There was always something new that popped up, and I just had to learn to take it a day at a time. Now I don't know how I ever lived a structured life because that's just not a reality any more. It has to be a day at a time. Someone came forward yesterday saying that they had something similar, and I asked, "Are you sure?" Because we haven't found anyone. She insisted, and we found out that the piece her son is missing is the piece that's inside of the big piece Chase is missing, so they did have some similarities. The biggest piece of advice I gave her was to live close to a hospital because that trip will kill you. It's too hard to be far from where your kid needs to be. He needs to be close to something in case something goes wrong, and it's nerve-wracking to have to drive somewhere that far, or have your child helicoptered or ambulanced there. I told her to live next to a children's hospital as that's what's best for your child.

Gerald: You guys are awesome, and he's a doll. Just watching him I see that he's great. I appreciate your taking the time to meet with me. I'm sure others will benefit greatly from your story. Any last thoughts?

Brandon: Going off what she said, it needs to be a qualified hospital, because we've been to the hospital locally, and it's not like the children's hospital that he goes to for most of his surgeries. Don't take the chance of having your child life-flighted when you know you could probably prevent that. You have to put him at the forefront of any decision that you make in your life. I graduate school next month, and every time I'm about to get a new job, the basis of where I work depends on him, because it's about whatever he needs. If I have to be somewhere, I don't want to be because of him, I'm okay with that because it's really all about him. For anyone who hears this interview, know that I'm a very open person, I don't have any issues with people contacting me asking about Chase, because I like to educate people and share with them the knowledge that I have obtained, because it might help them. I know some people who may cringe or who don't like to talk about their children with disabilities. I've even stopped in grocery stores to talk, ask what do they want to know, and I tell them if they have a few minutes, I'll tell them anything they want to know. It's no secret and nothing to hide, so share what you have and hopefully it can impact somebody in a way they need to be impacted, and give them some assurance or some help.

Gerald: Yeah, that's awesome.

Maria: A few last words I would say is to know that they will bless your lives more than anything you could ever give back to them. They are amazing people, and you can't forget that they are people. I cringe when parents tell their kids not to stare, to look away and don't ask. I say that, "No, they are okay, they can know everything about him." Like Brandon was saying, I encourage that. Don't teach your kids to look away, because they are people, and once they get to school and see kids who are different, they are going to think that they need to look away and not be their friend, and that is not what you want to encourage. I know they aren't doing that on purpose, it's something that's embedded in you, but I would encourage people to ask questions and encourage your kids to ask questions and befriend them.

Gerald: Cool, great, thank you both for taking the time.

Brandon: You bet.