

An Orange Socks Story: Georgia and Nick- Autism Spectrum Disorder

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In today's episode, I speak with Georgia and Nick about their son Lincoln, who was diagnosed with Autism. I know that you're going to enjoy learning from their experience.

Gerald: Georgia and Nick, thank you so much for taking the time to do an Orange Socks interview with me about your son Lincoln. Georgia, when did you find out that Lincoln was on the Autism Spectrum?

Georgia: When Lincoln was a year and a half, he was actually ahead in his speech, and in lots of different ways, he was a smart kid doing really well. The older he got, the more he lost speech and stopped interacting as much. He started having a hard time being out in public, so I started to suspect Autism. I felt like that was probably what was going on with him, and I didn't really want to face it, but I just didn't have a choice. On Thanksgiving Day when he was two years old, we were at Nick's family's house. Lincoln's first word was ball, and I remember saying, "Come get the ball! Come get the ball!" and he couldn't say the word ball. That was the moment when I knew something was up and that he had lost so much speech that he couldn't say that word anymore. That's when I knew I had to get him checked out, and it was shortly after that when we had him diagnosed.

Gerald: Nick, what were your thoughts when you found out that your son was Autistic?

Nick: I was in denial at first; it was hard for me to accept that something was wrong. It felt like the world was against me, and it was hard for me to accept. I looked past some signs, and I excused some things as just a phase or maybe he wasn't feeling well. It was hard for me; it was a struggle.

Gerald: Georgia, what have been some of the challenges?

Georgia: At first it was just getting to understand that even though I knew my kid, I felt like I didn't know my kid. After that diagnosis, I didn't know what to do. Now it seems silly to me, because he has always been the same kid; he never changed. I had to get to know how to interact with him so that he knew how to interact with the world. For me, the challenge in the beginning was knowing what to do to help him, because I had no idea. We went to early intervention, and it took forever. When we first met with early intervention, they were great, but they couldn't suggest services and they couldn't tell us what he needed. I absorbed as much material as I could; I got every book I could get, and I had wonderful neighbors who had kids on the spectrum who guided me as to some of the things that I should do. I really just

consumed information. At the time, we didn't have a lot of money, and we decided that I was going to take over part of that therapy. There's something called floor time that I started doing with him two-to-three hours every day, being on the floor with him and playing. I loved it, but I was burned out a little bit playing on the floor and trying to interrupt play -- that's the whole point of it, trying to interrupt and get your child to interact and play with you. For a kid who doesn't want to play and interact with you, it's a little bit tricky. In the beginning, what was so hard was trying to figure out the right therapy. Then this miracle happened, and the state of Utah started a lottery to cover behavioral therapy for kids on the spectrum because they hadn't covered Autism insurance before. They decided to do this lottery, and my son was a winner; he won the lottery! We got free therapy after that, and it made a huge difference. He's really not the same kid. He was low-functioning and had stopped talking almost entirely. He'd say mom and dad, but other than that, he stopped talking and was retreating into his own world. Now, however, most people can't even tell he's on the spectrum. The therapy has done so much. He has got his own little quirks, but every child does, and I love him and those quirks about him. In fact, in some ways, I feel like he's an easier kid than my other children because he's so predictable. He's honest and has such a good heart; he's an amazing kid, and I wouldn't change him.

Gerald: Nick, tell me about some of the joys.

Nick: A joy for me has been learning to like the things that Lincoln likes. I had some expectations of what it would be like to be a dad, that we would watch sports together, play catch and just be two peas in a pod, I guess. It has been really great getting to know Lincoln, because he is very complex and has things about him that are different than anybody I've ever met. He really is special. It's an honor for me to associate and to be part of Lincoln's life.

Gerald: Nick, you're making me wonder what his impact has been on your extended family. Georgia, what has been his impact on the extended family?

Georgia: They have all been really supportive. I hear sometimes stories where a family doesn't really understand and doesn't help out, but both of our families have been awesome, have been willing to accept his difference and think he's awesome because of it. We've been really lucky with our families; both of them have worked hard to understand who he is instead of expecting him to be like the other grandkids and cousins. He has some amazing cousins, too. They are just super special, don't you think?

Nick: Yes.

Georgia: He has some really special cousins who love him and play with him and think he's amazing. We've been really lucky with our extended family.

Gerald: That's super. Nick, if I were to come to you suspecting or perhaps even just getting a diagnosis that I had a child on the Autism Spectrum Disorder, what advice would you give me?

Nick: I would counsel you to keep in mind that reality is often different than expectations, and that's okay. Part of the joy of life, the mystery of life, is experiencing new things, learning new things, being challenged and working through difficult times. As crazy as that sounds, be patient; go ahead and grieve as you need to, but remember that Autism in particular is a very unique diagnosis, and kids on the Spectrum are all different. For the most part, every kid I've met on the Spectrum is a great kid, a kid who is genuine, who will be honest with you and will let you know their feelings. They have no guile is what I'm trying to say, and that is a precious quality.

Gerald: Very good. Georgia, last words?

Georgia: When you were talking just now about when Lincoln was first diagnosed, I remember looking around for helpful words of advice, and the best thing I ever heard was from a woman in our neighborhood who has a child who was 11 at the time. I remember being devastated, and I think she could sense that. She said to me, "I was where you are, and I remember thinking this is the worst thing in the world. How am I ever going to get through this? I look at him now, and I think what the heck was I so worried about? He's a great kid!" It doesn't seem to matter where your kid is on the spectrum; it seems like everybody feels the same way about their kid, thinking what the heck was I so worried about. You get to that point, and you love your kid, and you wouldn't want them to be different. I hear words about trying to find a cure for Autism, and I think, what is there to cure? He is exactly who he is supposed to be, and I don't want him to ever change. I want the world to understand him better, and I want him to understand the world, but I would never want to cure him.

Gerald: Thanks for listening to this episode. Orange Socks is an initiative of RISE Incorporated, a non-profit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website, orangesocks.org, for more stories and to find national and local resources to help parents of children with disabilities.