An Orange Socks Story – Nikki and Alan: Down Syndrome

Interviewed by: Dr. 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 Nikki and Alan about their son, Will, who has Down syndrome. Alan's coming to grips with the reality of having a child with a disability parallels my own experience, and speaking with Nikki and Alan brought back a flood of memories for me. As a family, they have done something very cool. Leveraging Alan's professional talents as a photographer, they created the nationally known, "Will Can Fly," calendars, which can be purchased at willcanfly.com. The proceeds of which benefit people with Down syndrome. I should also note that Alan has a blog called thatdadblog.com. You need to check it out.

Gerald: Alan and Nikki, thank you so much for taking the time to do an Orange Socks interview with me, I really appreciate it.

Alan: Thank you for coming out, we are excited.

Gerald: I'm interested to know about your experiences and thoughts around Will, who has Down syndrome. Nikki, how old is Will?

Nikki: Will is four.

Gerald: When did you find out he had Down syndrome?

Nikki: Just a few moments after he was born.

Gerald: Okay, same with me. I didn't know my daughter had Down syndrome until she was born.

Nikki: Yeah, it was a shock.

Gerald: What were your thoughts, Alan, when you found out you had a kid with Down syndrome?

Alan: I struggled with it when I first learned Will had Down syndrome. It's kind of an interesting back story. Nikki and I had been praying that things would go well, and I had a very strong feeling that Will was going to be different from my other children, but I didn't know what that meant. This was a month before he was born, at least, and I just kind of pushed that thought out of my head as we prayed as a family at night. Another week went by, and I had another strong feeling that Will was going to be different. I had a very distinct feeling that he was going to have Down syndrome, and it just shocked me because I don't know anyone with Down syndrome. We knew very little about Down syndrome, so it was odd that that popped into my head. I didn't want to make too much of an alarm with it, so I asked Nikki that night, "We are getting a little bit older, what are the chances of having a child with Down syndrome?" She mentioned that there's nothing that had been brought up by the doctor.

Nikki: Yeah, the ultrasound didn't show anything, and the doctor never said anything. Honestly, I was totally naïve about it. I thought, "I'm not over 40, so there's no way I would have a child with Down syndrome." I had no idea that 22-year-olds, or really young people could be affected.

Alan: Yeah, we had no idea.

Nikki: I just thought it was for older moms.

Gerald: Tell me about your adjustment process, Nikki.

Nikki: When he was born, I was super excited. He was here obviously, and it was really weird, like a total shock. The nurse and the doctor came back over right after and put him on my chest and said, "We need to talk to you about your son. We see some markers that point to Down syndrome." I looked at his beautiful, almond eyes, and I knew immediately that he did. It was a total shock, and I was scared because, like Alan said, I had never known anyone with Down syndrome, and I didn't know what that meant for me, or for him. Then I had a complete peace wash over me, and I knew that everything would be okay, so I didn't have that grieving process like Alan did.

Gerald: How long did it take for you to get over that grieving process?

Alan: Unfortunately, it took me a good month and a half to really move past that. My family was definitely the driving force to overcome those negative feelings. A big part of it for me was that I had a feeling that Will had Down syndrome, and I didn't know much about it. I didn't bring it up with Nikki after that one time, and when he was born, and they were cleaning him off, I could tell right away, just by looking at his eyes, that he had Down syndrome. It was like my world just turned off. The doctor was talking to me, and the nurse was talking to me, and I wasn't hearing a word they were saying. I was immediately thinking the worst. We didn't know anyone with Down syndrome, and we knew very little about it, and I thought that our world had come to an end. Yes, it was really hard for me, and unfortunately, I turned a very beautiful situation to a negative one.

Gerald: Has he had any physical issues, like heart issues or any sorts of things?

Nikki: He has been really healthy. He didn't have any heart issues. When he was about seven or eight months old, he developed infantile spasms, and he had that for about a month and a half before we even realized what that was, but they treated it and he's okay now. He hasn't had any seizures since then.

Gerald: Have there been any other hard issues that you've had to deal with, other than the acceptance and the grief of having somebody a little different from you? How has the reaction from family been?

Alan: Overwhelmingly positive for me. It makes me sound like a very pessimistic person, but just incredibly positive. I assumed that people would be a little more standoffish, and that they wouldn't necessarily feel comfortable approaching us, but family came to visit us who normally wouldn't come visit us after a child was born because of distance, just because they wanted to be around Will and wanted to meet him. Neighbors and friends just poured out, saying, "I know someone with Down syndrome, and they are an incredible person, and your life is going to be blessed." And just all these fun stories.

Nikki: He heard more than once, right after Will was born, "I'm jealous that you had a child with Down syndrome, I've always wanted a child with Down syndrome." I thought that was awesome.

Gerald: That's interesting. I'm looking at your family portrait, and I'm trying to figure out which number he is.

Nikki: He is number five.

Gerald: You have one after him, what has been Will's impact on your other children?

Alan: That's another thing that helped me move past the negative. It was so interesting for me to watch my children meet Will for the first time. They came into the room and immediately were treating him like their new brother, just very loving. When we explained to them that he had Down syndrome, I wasn't sure how they were going to react, but they immediately moved past it, like, "Okay, great, this will be fun." I feel like he has helped them be more accepting of those who are different. For example, maybe a year after Will was born, I was in the grocery store with Ali, how old was Ali then?

Nikki: She was six.

Alan: We were walking down an aisle, and Ali saw an older girl with Down syndrome, and she tugged on my arm and said, "Dad, look at that girl over there." And I immediately noticed that she had Down syndrome. My daughter said, "She has Down syndrome, she is beautiful." I don't know if she would have had that same reaction before Will was born. That right there was something that helped me to recognize that he's so young, but he's already teaching my kids so much.

Nikki: People email us saying that because of Will and our family's story, they are going to adopt a child with Down syndrome. That's amazing.

Gerald: That is a good segue into the calendar that you produce, tell me about that.

Alan: In 2015, we kick-started an idea about raising more awareness for Down syndrome. We had started taking pictures of Will flying as a way to sort of celebrate Will, and to show in a unique way the joys that we were having with Will. We also wanted to show that it goes further back, too, like when Will was one and learned to roll over on his stomach, he would flap his arms and legs like he was trying to fly. It was this big family joke that he was trying to fly, and that one day he would fly. One day my son and I were sitting here, and Will went into his flying pose, and I thought, “I’m a photographer, I’m going to help him fly. Let’s do this picture of Will flying, and we’ll send it out to family and say that Will took off. He’s flying!” Everyone knows he’s been trying to do this, so we took the photo and posted it to Facebook. Our immediate family thought it was incredible, and they loved it. Will had this big grin on his face, and I knew right away that this was something special, so we started doing more of them. I recognize that it was sort of symbolic in some ways, because even though Will had Down syndrome, we feel like as a family, he’s going to be able to do anything he puts his mind to, through the help of his family and his friends. Just because he has Down syndrome, doesn’t mean he’s going to be limited in the things he wants to do. We then thought, “Let’s make a calendar and try to raise money to provide some funds for a couple of Down syndrome foundations.”

Nikki: Half of the proceeds goes towards Ruby’s Rainbow, which helps provide scholarships for adults with Down syndrome to attend college. The other half goes to Reece’s Rainbow, which helps with adoptions all of the world of children with special needs.

Alan: So, our kick-starter was fully funded, and the next thing we knew, we were on the road where we got to meet a lot of families. We took a lot of Will Can Fly pictures. That was two years ago, and now we are on our third Will Can Fly calendar. We’ve met so many incredible people. It’s so inspiring, the number of people who are so giving and so loving. It has been a fun journey.

Gerald: That’s wonderful, good for you for doing something in a positive vein. If I were to come to you as a new parent, or I found out in utero, that I had this diagnosis of a child with Down syndrome, what advice would you give me? Nikki, you can go first.

Nikki: First, especially if you learned in utero, don’t stress out and don’t go to Google. There is a lot of information out there, but it’s not all positive information. Immerse yourself with other families who have children with Down syndrome, because it will completely ease your mind. You’ll get excited and be so happy that you’re going to be part of this new Down syndrome family, because it is a family. As soon as that child is born, or you know that you are having a child with Down syndrome, you’re embraced into this huge Down syndrome family, and it’s amazing. Take one day at a time. If your child has a heart condition or other needs that are stressful, just take one day at a time. You can’t stress about the future. You can’t stress worrying what if your child isn’t going to be able to talk or other things. Those are the things we thought, and you need to focus on the now, enjoying your child now and not worrying about the future.

Gerald: What would you add to that advice?
Alan: I would give them a high-five and say, “Welcome to the cool club.” We have met a lot of families who have a child with Down syndrome, and I have yet to meet a family who has a negative reaction to it, or a negative outcome from it. All of them have talked about how blessed their lives are, and I feel the same way. Will has helped me change in ways that I didn’t even know I needed to for the positive. I agree with Nikki that there will be a lot of unknowns, and there are going to be challenges just like with any child. I feel like our “average” children have special needs as well. Every kid has their own sort of special needs, Will’s are a little more apparent. But just take it one day at a time and immerse yourself with community. One thing that really helped me overcome my negative feelings and my struggle with learning that my child had

Down syndrome, was meeting other people who had children with Down syndrome, and getting an idea of what to expect. And to understand that yes, there are going to be challenges, but every family told me that the joys outweigh the challenges by far.

Gerald: And you’ve experienced the same thing? The joys outweigh the challenges?

Alan: Yeah.

Nikki: Definitely.