

Orange Socks Story – Bijan and Zach: DiGeorge Syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I had the great opportunity of sitting outside in beautiful surroundings, with Bijan and Zach for an Orange Socks interview. Primarily about their son, Jackson, who has DiGeorge syndrome, also known as 22q11.2 deletion syndrome. Issues were discovered with Jackson during prenatal examinations, leading their physician to offer abortion as an option. Advice they did not follow. Interestingly, during our conversation, they revealed that Jackson's twin brother, Walker, was recently diagnosed with autism.

Gerald: Thank you so much for meeting with me. Bijan, tell me, when did you find out that your son had a disability or a condition?

Bijan: We knew while I was still pregnant. I was having many complications. He had really high fluid, and his umbilical cord was not attached properly, so he wasn't getting the proper flow. I was closely watched, and after bedrest and many appointments, they basically told me that I'd have a very early delivery. Or because I was pregnant with twins, we could terminate baby B, which was Jackson, and go along with the pregnancy with baby A. We both declined immediately, and they were born at 31-weeks gestation. 40 weeks is full-term, 37 for twins.

Gerald: So you knew something was going on when you were pregnant?

Bijan: Yes, but they didn't know what because we had opted out of an amnio or anything like that.

Gerald: Right.

Bijan: There were soft markers indicating that it was a genetic condition.

Gerald: When did you actually get the diagnosis?

Bijan: Three months after birth.

Gerald: What was that diagnosis?

Bijan: He has DiGeorge Syndrome, also known as 22q11.2 deletion syndrome, so there's a deletion of his 22nd chromosome.

Gerald: So, Zach, what were some of your thoughts when you found out that you had a child who might have some issues?

Zach: I think for a lot of people, you can't really believe it at first. You just expect everything to go perfectly like every parent would. The first day was just denial, I

guess. I didn't know what it was. It took some research to figure it out, and looking it up was terrifying. But as the days went on, I grew a little more confident with trust and faith in the whole situation, and I knew it was going to be okay.

Gerald: Zach, what has been the hardest thing? You had twins, obviously that in and of itself is difficult, but what are some of the hardest things that have come about by having a child with 22q11.2?

Bijan: q11.2 deletion.

Gerald: Deletion syndrome, or it's called what?

Bijan: DiGeorge syndrome.

Gerald: DiGeorge syndrome. Have there been any particular challenges for you with a child with that diagnosis?

Zach: I think it sounds harder than what it really is, at least for the dad. I try to stay optimistic about everything, and I have no reason not to be. He's doing amazing. All you can do is be aware of the possibilities, while at the same time looking forward to sticking with it. You're his biggest support system, and he's our biggest support system a lot of times. So you just want to be there for him, help him develop and try to be a good dad. It doesn't really come down to anything besides that.

Gerald: Yeah, sure. How about for you, Bijan?

Bijan: The biggest challenges are seeing him go through everything he went through in the infant stage, I think. He had a 90-day hospital stay after he was born, he's had a surgery, he's been under anesthesia and he's had multiple tests run on him. In the beginning, it seemed like the cards were going to be stacked against him, and I think that was tough. They say not to live in the future, live in the moment, but as a parent, that's almost impossible. As parents, all we do is think about their future and what their life will be. I just don't want stuff to be tough for him, and in the beginning, it seemed like things were going to be a little tough.

Gerald: What types of things were they doing with him for those 90 days? I mean, why did he have to be there for 90 days?

Bijan: With this condition, a lot of kids have very serious heart conditions. We escaped that. He has an underactive thyroid, but they didn't figure out his thyroid condition for a while. He was very listless, wasn't eating properly and wasn't gaining weight. And they kept saying they knew it was a genetic condition, but they didn't know which one. They did a full-scale test on him, but it took so long to get the results back that he was seen by a couple of different geneticists who came by to try to figure out what it was before we got the results. Then when we did, it made sense.

Gerald: Okay.

Bijan: He was one pound, 14 ounces when he was born.

Gerald: Was he smaller than his brother?

Bijan: Yes, his brother was four pounds, five ounces.

Gerald: Wow, so maybe a little easier question is, Zach, what are the joys?

Zach: I think the first greatest joy with Jackson was seeing him smile and hearing him giggle, because when you're in the NICU, they're just pumping him with nutrients for as many calories as they can. They never know what they are going to get here in the NICU, and their faces are getting all puffy, and you're just trying to survive the day with them. You don't know what's going to happen, you never know. Just seeing him smile and looking you in the eye the first time was the biggest joy. Now they are three years old, and he's running around trying to mock everything Bijan and I do. I think the biggest joy thus far is his personality and his sense of humor. That has been greater than I could ever really dream of, so we both have a lot to look forward to.

Gerald: Oh, that's great. How about for you?

Bijan: The biggest joy is just seeing how far he's come. He still isn't the typical developing three year old, but our joys come from his successes and everything that he does do now, which we didn't know would happen. He does have such a great personality, and he's such a great kid. He's happy 99.8% of the time, so he's our whole family's joy.

Gerald: You found out that Jackson's brother has autism. What are your thoughts about now, with two children, one with something that is a pretty rare condition and the other one not so much as there are a lot of people who have autism? What are some of your thoughts, Zach?

Zach: After everything I've learned with Jackson, and just fighting with him and dealing with everything good and bad coming out of it. It was a long stretch of almost three years. I wasn't really surprised, I couldn't really be surprised by anything at that point. All I could really think was, "Here we go, let's just do it." We are already there for the boys, so all we can do is just do as much as we can and try to keep them happy. Try to be one step ahead and try to get them into any kind of therapies that can really help them.

Gerald: What were some of your thoughts?

Bijan: I felt like I had been hit with a MAC truck after everything. That's the truth, I just didn't see it coming. But like he said, this is our life, and these are our boys and they are perfect to us.

Gerald: Sure.

Bijan: When it was all happening, I thought I was going to have this one child who we would focus on, really work with and try to get him to be the best that he can be. And he would always have his brother to be there with him, and then his brother ended up having his own set of challenges.

Gerald: Sure.

Bijan: We're going through it.

Gerald: Having these boys and knowing that there have been some challenges, what has been the impact on your families and your respective extended families? You can start, Bijan, if you want.

Bijan: It has been extremely positive. We were the first in our families on both sides to have children with different needs or special needs, and I think it has opened up eyes in our whole family and just brought this sense of acceptance and love. We're very supported through them, and we're really thankful for that because we had no idea what we were doing, and no one else did either. We were all learning together, and helping the boys is everyone's main focus.

Gerald: Any thoughts you want to say on that?

Zach: Just to second that it's nice to be reassured by the comfort and support you have with your family and friends. Everybody I know has been there, and I wouldn't expect anything less, but it is nice to know how much they are there, and the way they take it helps me. I know it helps Bijan take it in stride and do what we need to as parents. We know we will return the favor down the road if anybody needs help. We are pros at dealing with stuff like this now. I'm glad I can be there for my friends and family if anything comes to that for them.

Gerald: Great, so I'll ask this for both of you; if I came to you, Zach, and said that I just discovered that my baby has a diagnosis of 22...

Bijan: ...22q11.2 or DiGeorge.

Gerald: 22q11.2 or DiGeorge Syndrome, what advice would you give me?

Zach: I would just tell you to hang in there, and sometimes having a label is the worst way to look at it. There is a label for everything, and the most you can do is

just enjoy your kids while you have them, because you never know, and that has been enough for me.

Gerald: What advice would you give me?

Bijan: Stay off Google, do not compare your child to typically developing kids or non-typically developing kids as every child is different.

Gerald: Right.

Bijan: We are all individuals and live in the moment. Don't live in the future. You cannot control the future, so there is no point. Enjoy your baby, and love him or her for who they are. Hope for good days always. You get through the hard ones with friends and family.

Gerald: Wonderful.

Bijan: Take care of yourself as parents. I'm not one shy to admit that I needed to seek help after everything, and I needed to go talk to somebody and let stuff out. I was so young when I got pregnant, everything just felt like it was constantly coming at me and I was very overwhelmed. One day I just looked up a therapist, and I went and had a session, and I went for a year. It was the best thing that I ever did for me and my children.

Gerald: Super.

Bijan: ...and my family.

Gerald: Great advice.

Bijan: You have to take care of yourself.

Gerald: Good advice.

Bijan: You can't take care of them, if you're not okay.

Gerald: Thank you both for sharing. You guys are awesome.

Zach: No problem.

Gerald: Thank you.