

## An Orange Socks Story: Jessie and Nathan- DiGeorge Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks Podcast where we are inspiring life despite a diagnosis I am your host Dr. Gerald Nebeker in today's episode I speak with Jessie and Nathan about their son, Ammon, who has multiple issues including tetralogy of Fallot with absent pulmonary valve, for which he has had surgery, DiGeorge syndrome and tracheomalacia. Ammon currently requires a ventilator, and you may hear it in the background. He is a beautiful little guy, and I know you're going to enjoy learning about him and Jessie and Nathan's story.

Gerald: Jessie and Nathan, thank you so much for taking the time to meet with me to talk about your son, Ammon. Jessie, tell me a little bit about Ammon's conditions.

Jessie: He has tetralogy of Fallot with an absent pulmonary valve and XYY, and he also has clubbed feet.

Gerald: Okay, when did you find out that he had some issues?

Jessie: It was at our 24-week ultrasound that our doctor noticed his clubbed feet. He also did notice that his heart wasn't functioning properly, so he referred us to a doctor. It was two weeks later at our appointment with them that we found out about his heart. At that appointment they did tell us that we had an option to abort. There's about 6 in every 1,000 kids have tetralogy of Fallot; however, combined with the absent pulmonary valve, it makes him about 6 in a million. It was interesting because our doctor pulled out this big book of different pages describing all different kinds of heart conditions and he had to draw ours in, and that wasn't necessarily comforting. I was used to the clinical side of things, I worked in a special care nursery, I had kind of an idea of what a NICU looked like and what babies went through during codes. And so, when our doctor started to tell us that he was going to need surgery if he was going to survive this, because as a mother you want to protect your children, and so he was in my little incubator at that time, you know, nothing could hurt him. He was breathing just fine, and when he said that he was going to need surgery, that was really hard for me to take in just because that's going to hurt him, you know, it's not going to be pain free. And so, we finished off that appointment. It was interesting because the doctors when they tell you about your child's diagnosis, it's not that you zone out, but certain things hit you different. So, when Nate and I walked away from that meeting there were certain things that he remembered and certain things that I didn't and vice versa, just as we were processing everything. But then another couple weeks had passed and as I was at an appointment for our maternal fetal medicine doctor, she noticed that I had a lot of extra amniotic fluid, so my body had actually doubled the amount of amniotic fluid in a couple of weeks. And she said that generally that's a sign that something is

wrong genetically, along with the heart condition and the clubbed feet. And so, we decided to do an amniocentesis. I think this was the most emotional that we had been. That was a really hard week because they have to prepare you for the worst, and they told us about different genetic abnormalities like the trisomy's, and they did tell us about Down syndrome and DiGeorge and those different things. However, trisomy 18 was the one that was scaring us the most because the child could only live for an hour, or a couple of hours or a couple of days or a couple of years. Anyways, so we waited a week for those results, and we were really grateful that he had DiGeorge and XYY, things that although had many unknowns, he was still going to be here. So, at that point our biggest hurdle was his heart condition and all the unknowns that came with that because of him being the 6 in a million. They had different people with that heart condition, every single one was so different and so there was a lot of unknowns. There were so many questions that we were asking that they just didn't know.

Gerald: So, Nathan, let me ask you, so you found out that you're going to have a child that would have some disabilities. The two of you opted to not end the pregnancy, but to have Ammon born, tell me some of your thoughts that were going through your mind when you found out about that diagnosis. What were you thinking?

Nathan: I think, honestly for us, we were a little more concerned for his lifestyle and for what he would have initially in his comfort. You know, the fear of losing him was the biggest for us, you know, him not even making it to a certain age. Especially when we found out that he could have some chromosome genetics, something that would only allow him to live for only a few hours. That was probably the feather that broke the camel's back for me because I felt that we could handle whatever came, but him not living was probably my biggest concern. It was something that I didn't take so well at the time, but eventually I just learned to let go of trying to control the situation and trust that, you know, everything would work out.

Gerald: Great, so Jessie, what's the hardest part in caring for Ammon? Now he's 7 months old, he's on a ventilator, I can see that as he's here in the room with us. But just tell me about what's hard about the care for him, or what's been the hardest thing in caring for him?

Jessie: When we entered this whole having a child experience, we anticipated, being that I worked with babies, that it was going to be a breeze. I mean, I felt like babies are only as hard as you make them. Sometimes, you know, we were anticipating changing diapers and car seats and that was it a feeding, and so just the normal things. And so, I guess for me the hardest part is not being able to just pick him up and walk around. I have to worry about a ventilator, I have to worry about tube feeds, you know, the humidifier and the millions of chords that are strapped on to him. I know that seems like something so simple, but I feel like it's the human in us where it's natural to compare ourselves to others. And so, I have a lot of friends who have children and it's hard when you see their children crawling, and you think, "Okay, how is Ammon going to do that when he starts to crawl?" He's going to have

to worry about this tube coming out of his neck, you know, if he has the braces on at that time. I feel like just the hardest part in all is just letting go of how it should be, and going with the flow and accepting our journey and how it is.

Gerald: So, Nathan, maybe a little easier question, what are the joys?

Nathan: Surprisingly he is a very happy boy. I think he is already a heart breaker and he's already teasing the ladies, so it's kind of funny to see that, but we can already see how he has taken some things from me and some things from my wife. And that's kind of interesting to see him grow and that he doesn't know any different. He's a happy baby, and he doesn't see himself as any different as any baby does at that age.

Gerald: What have been your joys?

Jessie: I would have to say the same. I feel like although we've been tried and it's comforting to see his joy and the love that he has and the tolerance that he has for so many things. And although we've been through a lot, I'm so grateful that he's here. The amniocentesis, the reason that was so hard for us was because, like my husband said, we felt like we could tackle anything together whether he be little different or not, we are just going to teach him to love himself and to come what may and love it and sort of have that attitude throughout life. And I'm really grateful that we get to see him as he grows up and all these different little stages, you know. I also have a couple of friends with babies who didn't make it, and I just think how hard it would be to not have him here. I guess that's our joy of no matter how hard it is, we are really grateful to have him, and he's taught us a lot. And with the hardest things of not being able to walk around with him, you know, he just brings so much joy that it makes those things so much more solid, so insignificant.

Gerald: Nathan, tell me about the impact his little life has made on your extended family?

Nathan: Well, I know for us, I think it's really softened a lot of hearts and made us realize how important family is as a whole. And when you realize that family is more important than the problems that you have, and that you can learn to let go and see how his innocence and his purity can be brought in to everyone's lives, and they can improve as a whole as a family. It's definitely when we bring him places or to family stuff, but the love and care that people have for him has just been very heart warming.

Gerald: Do you have anything to add Jessie?

Jessie: I wholeheartedly agree. His birth alone helped mend relationships that I didn't see being mended. For a while he's the first grandchild on my side, so you can just imagine all of my siblings love him. They are moving in and they are just having

them around every day to shower him with love, like they all play with him, just so fun to be around.

Gerald: If I were to come to you with the list of diagnosis that your son has if I had just found out that my child was going to have the same sort of things what advice would you give me?

Jessie: That it's going to be okay. It's okay to have hard days. He also has tracheomalacia and bronchomalacia, and so in the hospital when they tried to extubate him, he wasn't able to obviously breathe on his own. And so, when they are intubated or when they have the trach, you can't necessarily hear their voice. And so, in that CICU, the Cardiac ICU, we were in, you have different babies crying all around you. And I know it's something so simple, but the hardest thing for me was not hearing my baby cry. And I know that sounds, like, so insignificant, and I know that there are some people who might tell you, "At least he's alive," and it's true, but it's okay to have those days because it's part of the journey. And I feel like you can't have the good days without having the bad, you can't even recognize the good days without having those bad days, so it's okay to grieve. Know that your life is going to be different and that's okay because they bring their own blessings and they bring their own spunk and spirit into things. And although he has his challenges, I would not change a single thing about him because it's helped me grow so much. And I know that he's going to be a better person because of these things. I'm sure he will be more patient with certain things, he'll be more loving towards others who are struggling. It's allowed us to be more empathetic towards other people. Everything will be okay.

Gerald: Nathan, do you have any advice that you would want to share?

Nathan: Something that people who have played golf, there are very few golfers who are really good, and usually it takes one good shot to bring someone back to play golf the next time. And with our son, Ammon, and when he smiles it's like a good shot. And there's good shots all the time with a child like him, who's easily overjoyed to see people and recognize his parents, you know, recognize us when I come home from work. Even if it's a bad day at work, just seeing him smile when he sees me, that's probably the biggest joy. And there's no struggle that isn't worth it, basically, and that the joys and happiness will definitely be there no matter how hard the struggle is.

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](http://orangesocks.org) for more stories and to find national and local resources to help parents of children with disabilities.