

## 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 when our doctor noticed his clubbed feet. He also noticed that his heart wasn't functioning properly, so he referred us to another doctor. Two weeks later at that appointment, we found out about his heart. At that appointment, they told us that we had an option to abort. About six in every thousand kids have Tetralogy of Fallot; however, combined with the absent pulmonary valve, it makes Ammon about six in a million. It was interesting because our doctor pulled out a big book 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, so I had an idea of what a NICU looked like and what babies went through during codes. When As a mother, you want to protect your children, and he was in my little incubator at that time where nothing could hurt him and he was breathing just fine. When the doctor said that Ammon was going to need surgery, that was really hard for me to take in just because that was going to hurt him; it's not going to be pain-free. After that appointment, it was interesting because when the doctors tell you about your child's diagnosis, you don't zone out, but certain things hit you differently. 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 as we were processing everything. Another couple of weeks passed, and when I was at an appointment for our maternal fetal medicine doctor, she noticed that I had a lot of extra amniotic fluid; my body had actually doubled the amount of amniotic fluid in a couple of weeks. She said that generally that's a sign that something is wrong genetically along with the heart condition and the clubbed feet, 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. They told us about different genetic abnormalities like the trisomys, and they told us about Down syndrome and DiGeorge and those different things. Trisomy 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. We waited a week for those results, and we were really grateful that he had DiGeorge and XYY things and that although he had many unknowns, he was still going to be here. At that point, our biggest hurdle was his heart condition and all the unknowns that came with that. Because he was one of the six in a million, every single person with that heart condition was different, so there were a lot of unknowns. There were so many questions that we were asking that they just couldn't answer.

Gerald: Nathan, you found out that you're going to have a child who would have some disabilities, and 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: Honestly, we were a little more concerned for his lifestyle and for what he would have initially for comfort. The fear of losing him was the biggest fear for us, his not even making it to a certain age, especially when we found out that he could have some chromosome genetics that would only allow him to live for a few hours. That was probably the feather that broke the camel's back for me. I felt that we could handle whatever came, but his 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 stop trying to control the situation and trust that everything would work out.

Gerald: Jessie, what has been the hardest part in caring for Ammon who is now seven months old and on a ventilator? I can see that as he's here in the room with us, but tell me about what's hard about the care for him or what has been the hardest thing in caring for him?

Jessie: When we entered this whole having-a-child experience, because I worked with babies, we anticipated that it was going to be a breeze. I felt like babies are only as hard as you make them. We were anticipating changing diapers and having car seats and feeding, just the normal things. For me, the hardest part is not being able to pick him up and walk around. I have to worry about a ventilator, I have to worry about tube feeds and the humidifier and the millions of cords that are strapped on to him. I know that seems like something simple, but I feel like it's the human in us where it's natural to compare ourselves to others, and I have a lot of friends who have children, and it's hard when you see their children crawling. I 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 if he has the braces on at that time. The hardest part is just letting go of how it should be, going with the flow and accepting our journey the way it is.

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

Nathan: Surprisingly, he is a very happy boy. He is already a heartbreaker, and he's already teasing the ladies. It's funny to see that, but we can already see how he has taken some things from me and some things from my wife, and it's interesting to see him grow. He only knows that he's a happy baby, and he doesn't see himself any differently from any baby at that age.

Gerald: What have been your joys?

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

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

Nathan: It has really softened a lot of hearts and made us realize how important family is as a whole. When you realize that family is more important than the problems that you have, you can learn to let go and see how his innocence and his purity can be brought in to everyone's lives where they can improve as a whole and as a family. When we take him places or to family stuff, the love and care that people have for him has just been very heartwarming.

Gerald: Do you have anything to add, Jessie?

Jessie: I wholeheartedly agree that 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 imagine all of my siblings love him. They are moving in, and having them around every day to shower him with love and play with him is fun to be around.

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

Jessie: It's going to be okay. It's okay to have hard days. Ammon also has tracheomalacia and bronchomalacia, so in the hospital when they tried to extubate him, he wasn't able to breathe on his own. When they are intubated or when they

have the trache, you can't necessarily hear their voice. In that CICU, the Cardiac ICU, there were babies crying all around us. and I know it's something simple, but the hardest thing for me was not hearing my baby cry. I know that sounds insignificant, and I know that there are some people who might say that at least he's alive, and that's true, but it's okay to have those days because that's part of the journey. You can't have the good days without having the bad; you can't even recognize the good days without having those bad days. It's okay to grieve and to know that your life is going to be different, and that's okay. They bring their own blessings, and they bring their own spunk and spirit into things. Although he has his challenges, I would not change a single thing about him because it Has helped me grow so much. 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 and more loving towards others who are struggling. It has 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: People who have played golf know that there are very few golfers who are really good, and usually it takes one good shot to bring someone back to playing golf the next time. With our son Ammon, when he smiles, it's like a good shot. There are good shots all the time with a child like him who is easily overjoyed to see people and recognize his parents. When I come home from work, even if it was a bad day at work, just seeing him smile when he sees me is probably the biggest joy. There's no struggle that isn't worth it, basically, and 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.