An Orange Socks Story - Tamara and Matt: Down syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host Dr. Gerald Nebeker. I originally spoke with Tamara and Matt in 2017 when Tamara was pregnant with Grayson, who had a positive screening for Down syndrome.

Tamara: We're lucky that we took the prenatal test. I know that a lot of people in our community hate that test, they think it's a basis for a woman making a decision to have an abortion. That test saved his life, we wouldn't have known that he had Down syndrome and we wouldn't have been checking on him so frequently.

Gerald: And although the screening was positive, they still didn't know with 100% certainty that Grayson would actually be diagnosed with Down syndrome after delivery.

Tamara: But we always functioned as if he does have it.

Matt: We were preparing.

Tamara: Yeah, we were prepared for him.

Gerald: Among other things they prepared for Grayson's delivery with regular weekly doctor appointments.

Matt: The OB practiced the pregnancy differently because of the prenatal diagnosis.

Tamara: Because I was high risk, I was going in once every week. I would do a stress test and then they would do an ultra sound just to check on his growth. They realized that during the ultrasound that he was showing restricted growth, he was in the zero percentile of the measurement of his chest, they sent me to the hospital right away.

Matt: It was scary having the nurse check the baby's heart beat every couple of hours.

Tamara: I got steroid shots because they thought they would have to take him early at some point, whether it was in a week or a couple of days. They just wanted to prepare his lungs to be born sooner and they were actually going to let me leave the hospital. I said something was off and something didn't feel right and they decided to do another ultrasound before we left the hospital. Sure enough, it was not a stable environment for him to be there, he needed to be born immediately. So, I had an emergency c-section. Grayson ended up coming 6 weeks early.

Matt: It was scary to see my wife and my son to go through an early birth.

Gerald: Tamara and Matt didn't know immediately if Grayson actually had Down syndrome.

Tamara: It took us a week to find out. I got the call and I remember I was laying there with Grayson on my chest and I think I cried as hard as when I first found out the results of our screening test. It was maybe for like 20 minutes, and then I was like, "What am I crying about? This kid's amazing, he's here and he's everything that I didn't even know I wanted." Since then things have been amazing, he's the best.

Matt: Like Tamara said, he's a blessing.

Gerald: They feel blessed to be Grayson's parents.

Tamara: The experience is overwhelming at times and will move you in ways that you never thought you could ever be moved. I would do anything for him.

Gerald: At 18 months Grayson's personality is shining through.

Tamara: You just can't have a bad day with this kid. He's always happy, he wakes up smiling. More people should be like that in this world. If we had more people like him, the world would be a better place, that's for sure.

Matt: Every single day he shows us a little more of his personality, a little more of what he can do and we're just kind of taking it in day by day.

Gerald: They have seen Grayson progress and exceed all the doctor's expectations.

Tamara: He was 4 pounds 8 ounces, so he was a tiny guy. The doctors always tell you things, and I don't think this is just with Down syndrome, but anytime you have a premature baby they're like, "Oh, it's going to take a year or two years to catch up." Grayson has been making great strides since he was born, and his weight on a typical growth chart is in like the 50th or 60th percentile. The last time I checked through the last 11 months, he's been off the Down syndrome chart as far as weight is concerned. So, he's made great strides. Everything that I Googled or I learned from places that I should not have been paying attention to were all false. That's not to say that kids don't have certain health issues, but Grayson's been super healthy. He's had one cold at one year and he fought it like a champ, there really were no issues. He does have a small ASD that we are just monitoring over the next 3-5 years and we will see what we have to do when he gets of age. Other than that, he's a healthy kid. He's no different than anybody else's kid.

Gerald: They were told that Grayson would have a compromised immune system. So were my wife and I regarding our daughter with Down syndrome. We are all happy to report that our children with Down syndrome seem to be the healthiest members of our family. Tamara and Matt feel as many parents of children with disabilities feel, sometimes what the doctors tell you won't be the reality.

Tamara: I think it also puts things into perspective. When you are told you are going to have a child that's immune-compromised you start to do way more research than maybe a parent that has a typical child. You just listen to whatever your doctor tells you that they don't normally study Down syndrome. They don't look at the most recent research. You have to kind of become your own medical advocate, and I think that's what's kept Grayson healthy. We know how to take care of him and keep him healthy.

Matt: No one cares more about your kid than yourself. He's our son, he's our first kid, so we're just raising him and just learning how to be parents and how to be parents together.

Gerald: Tamara and Matt have some advice for parents who are fearful after a positive Down syndrome screening.

Tamara: When you see people with Down syndrome, you're going to hear them say things like I wouldn't change a hair on their head, or I would do this all over again. You will think that we are all crazy, but I promise you will get to the point that we're at. Grayson having Down syndrome is a part of who he is, and you are going to realize that this is the child that you are supposed to have. You're their parents for a reason, and I promise you that you will probably learn way more from him or her than they will every learn from you. I think that is the most important thing.

Matt: You know there is going to be hard times, have faith. It's definitely going to be a big growing experience for the better.

Tamara: We were planning on having children. We can't predict what any of our children are going to do, or anything that could happen to even a typical child. You could take your child on vacation and something could happen, and they could be paralyzed for the rest of their lives, you just can't live your life like that, it's going to be sad. You're going to think very bad thoughts in your head, and that's fine embrace those, don't feel guilty about it. It's just a part of human nature. But you're going to get to a point where this is going to be your greatest blessing.

Gerald: They remember when Tamara was pregnant with Grayson, knowing he had a positive Down syndrome screening and feeling distraught and sad wishing that they didn't have to face the trial of having a child with a disability.

Tamara: I thought those parents were crazy. I was like, "If you had a choice you would still want your child to have Down syndrome?" I did not understand it, and now I understand it because it is a part of who he is. I wouldn't want to change anything about that kid.

Matt: If we could have any control in this life, we wouldn't change one thing.

Gerald: They say the key to finding strength is to find a safe network of support.

Matt: Join a community. In this day and age where we have social media like Orange Socks or any other Facebook group, join that community. Dig in, ask questions, just dive in. There's going to be really hard days, but when that kid comes it's really going to be a joy.

Tamara: We have very strong online relationships through Instagram, through Facebook. Join smaller groups, I know that there are some larger groups that have some specific to your birth year and even down to your birth month. You can learn from different moms what kind of therapies they are going to, what kind of toys are best for your kids, what's working and not working for feeding and learning how to crawl and how to sit. There are so many resources, you're not alone. You're never ever alone.

Thanks for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a nonprofit 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.