

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 kind of think it's a basis for a woman making a decision to maybe have an abortion but that test saved his life because we wouldn't have known that there was a possibility 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 she 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 and they realized that during the ultrasound that he was showing restricted growth he was in the 0 percentile of the measurement of his chest they sent me to the hospital right a way.

Matt: It was scary nurse testing every couple hours baby's heart beat.

Tamara: I got steroid shots cause 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 and I said something was off and something didn't feel right and they decided to do another ultrasound before we left the hospital and 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 you know to see my wife and my son to go through a 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 and I got the call when that was out I remember I was laying here with Grayson on my chest and I think I cried as hard as when I first found out the results of our screening test and it was maybe for like 20 minutes and then I was like what am I crying about like this kids amazing he's here and he's everything that I didn't even know I wanted and ever 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 this kid's always happy he wakes up smiling more people should be like that in this world because 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 doctors expectations.

Tamara: He was 4 pounds 8 oz so he was a tiny guy you know 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 its going to take a year 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 all through the last 11 months he's been off the Down syndrome chart as far as weight is concerned and so he's made great strides and 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 there he has 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 but 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 and 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 but you find out not that your pediatrician doesn't have your child's best interest but 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 is that 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 and you will think that we are all crazy but I promise you you will get to the point that we're at because 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 and that you're there 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 its definitely going to be a big growing experience for the better.

Tamara: We were planning on having children and 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 its going to be sad and you're going to think very bad thoughts in your head and that's fine embrace those don't feel guilty about it its 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 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 and I wouldn't have 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 and dig in ask questions just dive in and there's going to be really hard days but when that kid comes its 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 like your birth month of other kids that have Down syndrome and 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.

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