Gerald: I am especially appreciative to Tamara and Matthew who had an Orange Socks interview with me. They are currently 30 weeks pregnant with a little boy who their doctor, based on genetic testing, believes has more than a 90% chance of having Down syndrome. I appreciate their honesty and candor; many parents will be able to relate to their feelings and experiences.

Gerald: Tell me your story, Tamara. You are expecting; how far along are you?

Tamara: I'm at 30 weeks.

Gerald: You got some news at some point in your pregnancy that you might have a child with a disability.

Tamara: Yes, we kept our pregnancy a secret for a little while, mainly because we wanted to tell my parents in person and they live in New York. We were planning on going back there for Thanksgiving. There wasn't any real reason behind it; we just wanted it to be a surprise. We didn't tell his parents or my parents; the only person who knew at that time was my boss. We finally told Matt's parents before we went to New York. We wanted to find out the sex, and we had the opportunity to find out the sex through a panorama, which is an NIPT test.

Matthew: That was at 10 weeks.

Tamara: Yeah, 10 weeks. I love my doctor, so I don't want to speak badly of her, but she kind of glanced over the fact that it was going to test for genetic issues and really highlighted that we could find out the sex of our baby. That was the big part of the test, and we would get the results the first two days that we were home in New York, which was perfect. When we were in New York, we got a call from my doctor, and I missed the call because I didn't have service, so she left a voicemail. It didn't sound very good, and immediately we were nervous. We couldn't get back in touch with her and didn't hear from her that same day, so we were both really nervous. The day before Thanksgiving, we went over to my friend's house for dinner, and it was about 9 o' clock in New York. I got a blocked call, and I wasn't going to answer it, but my friend said that it could be your doctor, so we took the call privately. Both Matt and I knew immediately that it wasn't good news.

Matthew: the tone of the doctor was very soft, wanting us to be consoled, and she was letting us know the results from the genetics testing, which, like Tamara said, we weren't prepped on, that it was going to be genetics. Since it was our first kid, we were mostly excited to find out the sex of our baby early on. Then the doctor led In and let us know what was going on with that test.

Tamara: We tested high-risk for Down syndrome. We don't know anybody with Down syndrome; it's not something that we grew up with, and we don't have people in our family. I've always understood it was something that was in older women, which I now know is completely false. Actually, the majority of Down syndrome children are born to younger women. A million things ran through our heads, and it instantly hit us that we both had tears in our eyes when we heard the news. We couldn't really finish the conversation with the doctor, and after we went back to my parents' house, that's when it really sunk in that this was a real thing for us. She told us that the test was 93% accurate, and we heard that our child had Down syndrome.

Matthew: Yeah.

Tamara: We didn't hear that he was high-risk; we heard that our child had Down syndrome, and for us, it shattered our world. To this day, I still think it is the worst thing that I've ever been through. It's definitely the worst thing we've gone through together in our marriage. It's like we are definitely at a different point, but it still hurts the same.

Gerald: Yeah, that would be a shock. So you got this news at Thanksgiving. What were your thoughts, Matt?

Matthew: The only reason it was a shock, just speaking from where we are now, is that we haven't been in the world of Down syndrome, so we are new to that and it's new to us. It was very scary at that moment. Since then, we have branched out and are more educated, and we have reached out to other organizations like Orange Socks and tried to familiarize ourselves with that type of life and diagnosis.

Gerald: This may be a difficult question, but it's not 100% sure that your child has Down syndrome; it's close?

Matthew: Yes.

Gerald: What are your greatest fears?

Tamara: I think my immediate fear was that we were going to have a child until the day that we died, and it also worried me about who was going to take care of my child when we were not around. I think that was my biggest fear, just not knowing if he'd be healthy or how long he'd live or if he would ever be able to have a normal life.

Gerald: What are your fears?

Matthew: Mine is more of a fear of day to day, so I don't look too far into it. Obviously we don't know how to care for a child with Down syndrome. I was more worried about my wife, her feelings, her fears and her emotions about the diagnosis; that's really where my focus was.

Gerald: Sure.

Matthew: My uncle has mental retardation, so I'm aware of that. He comes from a big family and is well-taken-care-of, so I was really never worried that Grayson, our son, would be not taken care of. I knew that, and I had faith that we would come together and would love and take care of this kid. We just find it very hard when we don't have him; we have the diagnosis, but we don't have him to love.

Gerald: Right, yeah.

Matthew: The difficulty was not having someone or not having that physical person to hold in your hands.

Gerald: Do you think it's easier to have the diagnosis before the birth, or would it be easier after? I mean, you obviously don't have a choice here.

Matthew: Great question. We've contemplated this. We are sitting here a few months away from birth, and we often wonder if we would rather have known about the genetics testing before, or would we want to have found out right after birth. I would have liked to have been educated on the genetics test itself, the statistics that go along with it and the results, and have been guided on how to interpret the results of the test.

Tamara: it wouldn't have been so traumatizing for us.

Matthew: Yes.

Tamara: Nowadays, the first thing you do is Google it.

Gerald: Right.

Tamara: Googling is not your friend sometimes. In hard situations, you find the worst of what you're looking for. We just didn't know anything about the test, so we had to find it all out on our own. We didn't see a genetics counselor for another week and a half or two weeks afterwards, so we weren't able to discuss these concerns except with people on the Internet, or see information besides what we saw on the Internet. Back to your question of whether it would be better before or after, for me, there is no way to be able to tel.l I think I would prefer not to know period. I've had this conversation with other moms who have children with Down syndrome who found out afterwards, and they have looked at it from my perspective andsaid they would not have wanted to know, that they would think about that all the way up until the time he was born. We do, but I don't know if it would be any better thinking our kid was going to be born like a typical child and then being told that he has Down syndrome after he is born. I don't know how I would feel about that, so we're prepared right now.

Matthew: Yes, the super positive is that we've had time to be diving into this community, educating ourselves and following everybody we can on social media, which has been great. One of our favorite Instagrams is nothingdownaboutit. We love that Instagram, and watching that every single day has been good, because now are prepared.

Gerald: I'm just curious because I had this happen to me when people found out that I had a child with Down syndrome, very well-meaning people giving me advice. Do you have that happen? I'm just curious if that has happened to you.

Matthew: Not yet, but I can see that not everyone has….

Gerald: Okay.

Matthew No, everyone really hasn't.

Tamara: He hasn't because he doesn't talk about it.

Matthew: I talk about it, but they say to just have faith, that everything will be okay, so no real advice yet, just kind of have faith and you're going to be okay.

Gerald: I did find it interesting that the people who were the quickest to give me advice and comfort were people who did not have a child with a disability.

Tamara: Right.

Gerald: For me, I found more validity from the people who did.

Tamara: Yes, 100%.

Gerald: I don't know if that's been your experience.

Tamara: My experience is different than Matt's, mainly because I just went home to have my baby shower, so it was spoken about with my family and friends while I was there. Because we are in this kind of weird, I don't even know what to call it, purgatory of whether or not our child has Down syndrome, it's not so much that people try to give us advice on how to parent a child with Down syndrome or a disability, but more "I wouldn't worry about it; those tests are always wrong," or "We know somebody had that similar thing happen," or when people don't really know your story.

Gerald: Right.

Tamara: Maybe you had something come up in an ultrasound, but you didn't have the test that I had or the markers that were found on our ultrasound, so our situations are not the same, or something came up in their ultrasound or during their pregnancy that they want to try and relate it to, but it's just not the same. I understand that you have fear for your children, and I totally respect that, and I know that it's well-meaning, but it's not that the same.

Gerald: Sure.

Tamara: Sometimes it’s hard to just bite my tongue and say thank you like I appreciate that. Sometimes you want to say, “You don’t know what’s going on,” but there’s no amount of talking that I could do to make somebody understand what it feels like. There’s nothing that I can say.

Gerald: I think you hit on it, because you have to walk down the path to get it, and the only people who get it are those who have walked that same path. Yet everybody has their own adjustment period, faster or slower. To be honest, I don’t have a lot more questions for you, but I’m really excited to interview you after your baby is born and to follow this along if you’re willing.

Tamara: We are definitely willing.

Gerald: Get the baby home, get adjusted, and we find out if he has a name, right?

Tamara: Grayson.

Matthew: Grayson.

Gerald: Grayson. Okay, when you get Grayson home and we find out if he has Down syndrome or not, and let’s say he does, then I’m really interested to do just periodic little updates.

Tamara: Sure, yeah.

Gerald: I’m just really curious to document your progress, if you will, because I think there are people out there who are struggling exactly with the same thing. I know when I was going through that, I valued the people who could tell me exactly what I was feeling at a particular time.

Tamara: I think it’s going to start to become more common, because this test is becoming more common where it has kind of been in the shadows. For the last five years, it has been offered to women In low-risk categories. No matter if Grayson has it or not, we’ve learned so much, and we can’t turn our backs on this community; this is going to be what we advocate for.

Gerald: You mentioned something that I thought was interesting before we started, that you had already talked about whether you had a child with disabilities, what you would do, and you already made that decision.

Tamara: Yep.

Gerald: What was that decision?

Tamara: That we would keep him no matter what.

Matthew: That we would love the heck out of him.

Tamara: We heard his heartbeat before we took the test, and I would always think about that if we aborted him. We couldn’t fathom it. We see how much joy they bring to their families, and they can have completely normal lives. They can be successful and fulfill their dreams just like any other child.

Matthew: We notice Down syndrome a lot more now; we are a lot more aware of it now.

Gerald: Sure.

Matthew: We see it everywhere; it’s part of our community.

Gerald: You guys are awesome. Thank you, and thank you for letting me check in with you periodically.

Tamara: Yes, for sure.

Gerald: Your story is important.

Matthew: Absolutely. We believe in what you’re doing overall.

Tamara: It has helped us tremendously. Orange Socks is amazing, because I started sending him stories when I found you guys. It puts things in perspective. This is not necessarily something we thought we’d be getting ourselves into, but we can also be in a completely different situation that we wouldn’t want to see ourselves in, and we see families that are getting through it just fine. He is going to be fine no matter what.

Gerald: Amen. Thank you.

Matthew: Yeah.

Gerald: I am grateful to Tamara and Matthew for giving us a snapshot of their life in real time, and thankful that they have agreed to follow-up interviews after their baby is born.