An Orange Socks Story - Tiffany and TJ: Down 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 this episode, I speak with Tiffany and TJ about their son, Austin, who has Down syndrome. They're heavily involved with the local Down syndrome association in their community and invited Orange Socks to participate in a fundraising effort, a half-marathon. I didn't run the race, but I really enjoyed the many people that I met at the event. I know you're going to enjoy hearing from Tiffany and TJ.

Gerald: Tiffany and TJ, thank you so much for taking a few moments out of your busy life to talk with me about your son, Austin, who has Down syndrome. He's how old?

TJ: Six years old, he turned six yesterday.

Gerald: Six years old, that's great. Tiffany, when did you find out that Austin had Down syndrome?

Tiffany: Officially, we found out about a week after he was born, but when he was born, I knew he did. I had him at home, and my midwife couldn't officially diagnose, but I had worked with adults with intellectual disabilities before at a facility in town, and the shape of his eyes made me know that he had Down syndrome.

Gerald: You had no clue before he was born?

Tiffany: No.

TJ: None. We had to force it out of the midwife because actually she can't...

Tiffany: She just can't officially diagnose.

TJ: She couldn't officially diagnose, but she did share what she thought.

Tiffany: She had delivered other children with Down syndrome, so she was well-experienced and really wonderful.

Gerald: Super. What have been some of the challenges that you've had so far in his six years?

TJ: Potty training right now is one. He potty trained fairly early.

Tiffany: He was three.

TJ: But he has been having some issues right now.

Tiffany: Regression, that can happen.

TJ: We are trying to work through that. He has always been pretty verbal. We knew pretty early on that he was going to be verbal, but walking is something that took him a little longer to do.

Tiffany: Yeah, he was three before he walked.

TJ: Yeah, he was three before he really walked.

Tiffany: In fact, we potty trained him before he could walk on his own. He had a walker, and he did really well for a good year and a half, but not great. That happens with all kids, they can have regressions.

TJ: There hasn't really been anything big, we are very fortunate.

Gerald: That's great. What have been some of the joys that you've experienced with him, Tiffany?

Tiffany: I definitely think when he has hit milestones, that took a long time. Those were precious and more important than I had remembered before with our other kids, that some things came to them quickly and they knew how to do that. We didn't feel the triumph of it as much, but those have been some really big joys. He loves people, and he loves to entertain. He's a big people-person, he wants to be with people and learn. He loves books, that has been a huge joy that he loves books. He's not reading yet, but he's getting some words here and there. Some basic things are appreciated more than with my other kids that came easier to them. I've really found a lot of joy in small things.

Gerald: TJ, tell me, you have two older children.

TJ: Yes.

Gerald: Tell me the impact that Austin has had on them.

TJ: For our daughter Jade, it has made her a lot more open and aware of her surroundings. I can see how she interacts with other kids who have Down syndrome or kids who have any other kind of disability. She's very cognizant of how she can help others and how she can interact with them. For James, one of the things that was interesting to me was that soon after Austin was born, we had a friend whose son has SMART, spinal muscular atrophy with respiratory distress. It's a very rare disorder, and so shortly after Austin was born, James decided to do a birthday where instead of getting gifts for himself, people would donate to this organization that helped kids with SMART. For our children, it has made them more aware of the world around them and how they can help other people.

Tiffany: They've seen us enough with advocacy, working with Down syndrome awareness month and with World Down Syndrome Day coming up. I think that recognition made them want to participate. There was a time where I thought they didn't need to do anything, because I didn't want to pressure them to do stuff, but they said they wanted to do something. Even today, we were sharing about something at school so that they could celebrate it with their friends. I think that's a really good opportunity.

Gerald: What has been his impact on your extended family, Tiffany?

Tiffany: Oh, they love him, they just cherish him. TJ and I are both only children, so our kids are spoiled rotten by grandparents and great grandparents that live within Texas or close by. Most of them live here in Longview, TJ's mom lives in Houston, so she's not too far away. There was some hesitancy at first, not in loving, they've always loved him so much, trying to understand what Down syndrome is and what that diagnosis means, and a lot of questions to try to understand better. They really just want to help him and love him and be with him. I don't see a lot of difference between Austin and our other kids as to how they've treated him or loved him more. He's the youngest, too, so he's the more cuddly of the three.

TJ: It has been interesting to watch, because there's a generational viewing of Down syndrome, or really any intellectual disability. We were never really bummed about it, it was something that we thought, "Okay, here we go. And this is fine." For them, watching how their preconceived imaginings of what it might be like to have a child with Down syndrome change because of how we've treated Austin and how Austin has grown up with our other two children, has been really interesting to watch.

Gerald: Tiffany, if I were to come to you, realizing I had a kid with Down syndrome, what advice would you give me?

Tiffany: They'll bring so much joy to your life that it's not something to worry about or have a lot of concern about. Austin hasn't had medical issues that have caused him to be in the hospital a lot, and there are some who have to deal with that. My personal experience has been that I have no regrets, not that I had a choice to change my mind, but I feel like I've been blessed to know him and to be his mom. It's not something I would worry too much about, because I try to treat him as closely as I can to my older kids. I know he may not meet the milestones at the age my other kids did, but wherever he is, we work on the next step, whether it's learning to get dressed himself or potty training. He has always been a good eater, so that hasn't been a big issue, but there's a variety of issues, and you don't know anything really. You can't plan out your life perfectly, there is no way to do that. Accepting a diagnosis, and learning and growing from that has helped us to embrace who he is as a person and not just think about his diagnosis that often. Most of the time, he's just part of our family. I would tell another parent that same thing. I wouldn't worry, I would just let life come, and do what you need to at different times, but don't worry a lot. It's never as bad as you think. There's so much joy to experience that you won't miss out on what you think you might be missing out on.

Gerald: Super, TJ, did you have anything else to add?

TJ: I would agree with what Tiffany said. I think a lot of people find themselves with maybe this vision in their head of what this perfect family is going to be like, and a lot of people don't envision having those challenges that come with having a child with a disability or Down syndrome or whatever it might be. I think that just accept and understand that it's okay and that it's different than how you thought it was going to be. In a lot of ways, it's better, because you get to meet a whole group of people that you wouldn't have gotten to meet otherwise. You get to learn a whole new set of skills and come in contact with people who really change your life, so don't sweat it, it will be okay.

Gerald: You two are heavily involved in an association in your town called the East Texas...?

Tiffany: The East Texas Down Syndrome Group.

Gerald: The East Texas Down Syndrome Group. Did you form that group?

Tiffany: No, we started attending after Austin was born six years ago. I went to the first meeting. I'm a social worker, so I like group things and support. I thought, "Okay, he has Down syndrome, let's go meet some people who have children with Down syndrome and learn from them." I started attending, and I worked for the group for a little bit part-time. Now I'm just a volunteer again, and that's a good place to be too. It's amazing the connections that you make meeting people through that group, finding good friends who understand things differently than most. I still have lots of friends who don't have a child with a disability, but with the friends that I've met through the group, I can call them about something, and they will understand something that somebody else wouldn't. Facebook messages or finding ways to connect with them has been really helpful along the way. I'm a big advocate of life-long learning, no matter who you are if that's helpful, so I just felt like when Austin was born, that this is something else we need to learn about. We can do it if we reach out. We've gone to national conventions and learned a lot from experts and other parents. It has been an amazing world to step into and to learn from so many people.

Gerald: I think it's great that you two have been in this group. It was my privilege to attend a Buddy Walk/Run?

TJ: We have our Buddy Walk.

Tiffany: In October.

TJ: Not till September or October

Gerald: So, this is separate.

TJ: Yeah, the run that you came to was actually the Longview half-marathon that Ann books. It is actually an organization that I think is international or national?

Tiffany: They are national.

TJ: They make the Ann Trike, which is a trike that is ...

Tiffany: Adaptable.

TJ: It is an adjustable bike to help kids to learn how to ride, or to help them with their different muscular coordination.

Tiffany: A lot of physical therapists use it to help them.

TJ: They had done this run for years at the Longview Running Club, and they decided for whatever reason not to do it this year. This year was its 10th or 11th year. We were trying to find a way to do a 3.2 mile run in the community to bring acceptance and inclusion into the community. I found out they weren't doing the half-marathon. I have a passion for running, I've had it since just before Austin was born, and really that's when it started. I jumped at the opportunity to direct it, so it became the responsibility of the group. We didn't look at it as a fundraiser, we have a fundraiser. The Buddy Walk does well for us, but this was a different crowd to get the word of acceptance and inclusion out to them. At the Buddy Walk, we tend to draw a lot of our families, our friends and people that we already know, and it gets covered by the local media. This was just a different group that we could reach out to.

Gerald: Well, a shout out to you. It was fun to participate in that, and it was well-attended.

Gerald: Thanks for listening to this episode. Orange Socks in 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 for more stories and to find national and local resources to help parents of children with disabilities.