

## An Orange Socks Story – Tori and Matt: Cerebral Palsy

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I am grateful that Tori and Matt took the time to meet with me and talk about their life with their daughter Lana, who has cerebral palsy because of a congenitally acquired Cytomegalovirus.

Gerald: So Tori, when did you find out that your daughter had issues?

Tori: When she was about nine months old and she hadn't sat up or rolled over or anything, that's when we realized this is more than just her being a really chill baby. She was the most easy-going, happy little baby, just doing things on her own, and we attributed that to her laid-back personality. But by nine months, she wasn't doing anything, and then we started getting concerned. Our Pediatrician referred us to Primary Children's where we met with a pediatric developmental specialist and got an MRI done. So she was probably about a year old when we actually got the MRI and got a diagnosis.

Gerald: And what was the diagnosis?

Tori: When they did the MRI, they told us it could be one of two things; one was Cytomegalovirus and the other was some weird genetic mutation that the odds of us having were extremely slim, especially since it only really manifests itself in people of Middle Eastern Decent, and we're not, so CMV it was.

Gerald: Matt, what were your thoughts when you found out that your daughter had a diagnosis?

Matt: It wasn't anything that I could have ever expected. I'm the youngest of six kids, and all but one of my siblings had their own kids, and none of them had one with a disability. When I found out that my little girl did, it was tough, but we knew that she was determined to do things when she wanted to. She usually doesn't want to do things and is just content to lie on the floor, but when she does, she figures it out, so she's definitely been an inspiration.

Gerald: What types of issues does she have? Tori, what is her diagnosis?

Tori: It's CMV, a common virus that anybody can get and 80% of the population will end up getting. It's not a big deal; it's like you'll get a cold and chances are you might not even know that you have it. It's only a problem for someone whose immune system is compromised, or if you get it when you're pregnant which is what causes disabilities to an unborn baby. I don't know when I got it, and I honestly can't even remember being sick at all when I was pregnant. For me, when I heard that diagnosis and then learned about it, I had no idea; I had never heard of it. The doctor never mentioned it, and it's more common in Down Syndrome.

Gerald: How has this manifested in your daughter?

Tori: CMV causes a wide range of disabilities. In her case, she has Cerebral Palsy which is the big one.

Gerald: CMV caused this Cerebral Palsy?

Tori: Right, the virus caused Cerebral Palsy. She has problems with eating and speech. She doesn't talk; she says a couple of words like mom and I did it, but that's about it. Along with those is the doctor's diagnosis of failure to thrive. She has slight scoliosis because of her hips. Normally with CMV you'll see vision and hearing loss, and from what I've read, that's usually what will tip doctors off, and they will test for it as a newborn, but when she was born, she was pretty much your perfect, healthy, little tiny baby. She didn't have any of those problems, so for her, it's mostly her walking, talking and eating though she's actually quite intelligent. Her mental capabilities don't really match her physical ones.

Gerald: She doesn't have an intellectual disability. How do her physical disabilities manifest?

Tori: She picks up on signs. They have little choice boards at school, and she's learning how to make choices. She challenges things in her own way, and she understands a lot of what we say, probably more than I think she does.

Matt: Re the words hold on and wait, she doesn't seem to like those words.

Tori: She's also three, so...

Matt: ...so it's typical three.

Gerald: Matt, what are the hard things for you in caring for your daughter?

Matt: Probably just the fact that I'm usually not around very much. Throughout the day I'm in school, and because of Lana's disability, I don't want Tori to have to work, so I also have a full-time job, plus right now I am doing a part-time job. Life is pretty busy for me, and I'm not usually home very much, so I can't really do much to help throughout the day. I get home pretty late, so usually the weekends are when I try to do as much as I can to help out with her physical therapies and just making sure she knows that even though I'm not home very much, I still love her.

Gerald: What are some of the challenges for you, Tori?

Tori: As a parent, it's always hard to see your kid struggle with something. Dinner time is probably my least favorite time; trying to get her to eat food and put on weight is a struggle. I guess I would say the hardest thing is wondering how people are going to treat her. She can't

get up to go play with kids; they would have to come play with her. She's three, so no other three-year-olds are going to pick up on that; they want to be up and running around, and she can't do that. I think those are the hard things. When we had to go do the MRI or the swallow study or other things that are painful or hard for her, she doesn't understand why we're doing it, and she would look at us like why are you doing this to me? So those are hard. They're good for you, but I'm sorry you don't like it type of thing.

Gerald: Easier question: what are the joys?

Tori: Oh, man, she is such a happy little girl. This is her life; she doesn't know any different. She's just a joy to be around, and she's sweet. The fact that one of the things she does say is I did it to whatever she does, big or small, and she gets so excited and says "I did it" in her little voice. She's just a sweetheart. There is so much joy in seeing her accomplish things. She can crawl now, and when she learns and knows sign, and she gets so pleased with herself -- all those things are just a joy.

Gerald: Super, Matt.

Matt: I would have to echo that, and I don't know of very many people who have met her who don't say that she is just the sweetest little girl, our bundle of joy.

Gerald: So, Matt, if I came to you just having learned that my little girl has a similar diagnosis as yours yet she is a baby so you have a few more years of experience, what advice would you give me?

Matt: Probably to not treat her any differently than any baby. Just like our youngest, she needed care and attention, and to just love her as much as you can and to help her try to understand that even though she is different, she is still a little kid and still can grow up knowing how much she is loved.

Gerald: What would you add to that?

Tori: I would say early intervention is extremely important. Before we had a diagnosis, we started in with an early intervention program they have up here, and she still goes to therapies several times a month and every other week. She does it all: physical, occupational, speech, feeding. They are always joking at the hospital that we should just move in there because we are there all the time. Then connect with other parents. I'm on a Facebook page for parents who have children with CMV, and it's great, because you can ask questions and you know that these people aren't going to make you feel dumb; they will answer your questions. I've answered questions for parents, and it's a nice community. Find your community, and even though it's hard, try not to stress too much and just enjoy your day to day and celebrate whatever milestone your child hits. Whatever they do, you make it a big deal, because it is a big deal. Love your kid and go ahead and make memories with them. We took her to Europe with us on a vacation with my family, and she did great. A lot of people worried "Oh, if I have kids

especially if they have disabilities, we're not going to be able to do these things," but you still can. you can still do all those things. you can go on vacations and make all those memories; you just might have to do them a little differently, and that is okay.

Gerald: That's great. I appreciate you guys. Thank you, Matt, and thank you, Tori, for meeting with me. Any closing words?

Tori: One thing that is important with CMV is that it is something that is preventable, or you can try to prevent it by washing your hands and not sharing food or drink with small children because they are usually the culprits carrying the virus. It's something that I've learned, and I want to spread awareness about it because although she's kind of on the mild end, there are kids out there with the same thing who have more struggles. It's one of those things that you might feel guilty about because i could have prevented this but i didn't know anything about it. I wish the doctors would be open and share this information with their patients. I also read a really great quote that said a disability community is the largest minority community that anyone can be a part of. It's not just something you are born with; at any time, it could happen to anyone. I guess it's just celebrate life, help each other out and be kind. That's what I've learned from having a child with a disability. I feel like she is helping me become more patient and more aware of the fact that everybody has struggles, so just be kind because you don't know what someone is going through.

Gerald: Let me ask you this question. I forgot to ask it earlier, but what impact has she had on your family, your extended family, your neighbors and friends?

Tori: They just absolutely love her. She was the first grandchild for my parents, and they just adore her. They adore all their grandchildren. Seeing them become grandparents, seeing my siblings become an aunt and uncles, just shows that she brings joy wherever she is. Her teachers and people we meet see just a happy little girl, and they make her laugh. We meet people who know sign language and do some signs with her. She just has a way of bringing people together and bringing a smile to their faces. She learned how to crawl at my parents' house back in Virginia, and we were all like yeah, big party, so turn everything into a big party.

Matt: With my family, I'm the youngest, so she has a lot of older cousins and we see how caring they are for her. The older ones don't pay too much attention, but they don't pay too much attention to any of the younger kids. The younger ones come to her and try to play with her even though she can't move around. It has been really nice, and my family has been really supportive. They ask us how she is doing all the time, and she loves my mom. We call her Mamaw, and every time we get to go down and see her, we ask, "Do you want to see Mamaw?" and she just gets her huge grin on her face, so she has had a big impact on my family as well.

Gerald: Terrific.

Tori: To see other people love your kids and to see your family love your kid, even your child who is a little different is heartwarming. I guess that's a good way to put that.

Gerald: Terrific. Thank you both.

Tori: You're welcome.

Gerald: It was an honor to be here.

Matt: Yeah, thank you.