An Orange Socks Story: Tori and Matt – Cerebral Palsy Due to CMV

Interviewed by: Dr. 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 congenitally acquired cytomegalovirus.

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

Tori: well when she was about nine months old and she hadn't sat up or rolled over or anything. That's when we were kind of like, "Okay this is more than just her being a really chill baby." She was the most easy going happy little baby and just doing things on her own and so we attributed that to her laid back personality, but by 9 months and she's not doing anything and then we started getting concerned. And our pediatrician referred us to Primary Children's, and so we met with a developmental, or pediatric developmental specialist and we got an MRI done. And so she was probably about a year when we actually got the MRI and got a diagnosis.

Gerald: And what was the diagnosis?

Tori: Well, when they did the MRI they told us it could be one of two things, and one was cytomegalovirus, and the other was some weird genetic mutation that the odds of us having was extremely slim, especially since it only really manifests itself in people with middle eastern decent and we're not, so CMV it was.

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

Matt: Well, it wasn't anything that I could have ever expected. I'm the youngest of 6 kids and all, but one of my siblings had their own kids and none of them had, you know, one with a disability. And so and when I found out that my little girl did it was tough. But, you know, we knew that she was determined to do things when she wanted to, like usually she usually doesn't want to do things and she is just content to lie on the floor. But you know, when she does she figures it out, so she's definitely been an inspiration

Gerald: So, what type of issues does she have, Tori? How does her diagnosis, which is…?

Tori: Its CMV. CMV is, it's a common virus that anybody can get, and like 80% of the population will end up getting it. And it's not a big deal, it's kind of like you'll get a cold. So chances are you might not even know that you have it, and it's only a problem for someone who's immune system is compromised, or if you get it when you're pregnant and that's what causes disabilities to an unborn baby. So, I don't know when I got it, and I honestly can't even remember being sick at all when I was pregnant. And so, for me, hearing that diagnosis and then learning about it, I was like, "What the heck?" I had no idea, I had never heard of it, the doctor never mentioned it and its more common in Down syndrome that people don't know about it.

Gerald: So, how has this manifested in your daughter?

Tori: CMV kind of causes a wide range of disabilities. For her, she has cerebral palsy is kind of the big one.

Gerald: And CMV caused this cerebral palsy?

Tori: Right, because of the virus it caused cerebral palsy, eating issues, she has problems with eating, speech, she doesn't talk, she says a couple of words. She says, "Mom," and she says, "I did it," but that's about it. And, you know, along with those is you get the doctors diagnosis of failure to thrive and she has slight scoliosis and because of her hips. And normally with CMV you'll see vision and hearing loss and that's usually, from what I've read, it what will tip doctors off and they will test for it as newborn. But as she was born, she was pretty much your perfect healthy little tiny, but didn't have any of those problems. So, for her it's mostly, you know, her walking, talking and eating. For her though, she is she's actually quite intelligent, like her mental capabilities doesn't really match her physical.

Gerald: So, she doesn't have an intellectual disability, hers are manifested with the physical?

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

Matt: And for the words, "Hold on," and "Wait," she doesn't seem to like those words.

Tori: But she's also three, so.

Matt: So, it's typical three.

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

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

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

Tori: Well, I mean, as a parent it's always hard to see your kid struggle with something. Dinner time is probably my least favorite, trying to get her to eat food and put on weight is a struggle. I guess I would say the hardest thing is like wondering how people are going to treat her, you know. She can't get up to go play with kids, they would have to come play with her. And she's three, so no other three-year-olds aren gonna pick up on that, they wanna be up and running around, and she can't do that. And so, I think it's those are the hard things. And whenever we had to go do the MRI or the swallow study, like things that are painful or hard for her and she doesn't understand why we're doing it, and she just 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, you know. This is her life, she doesn't know any different. And 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. She gets so excited and she's just, "I did it," in her little voice. And she's just a sweetheart, there's so much joy in seeing her accomplish things. She can crawl now, and, you know, when she learns a new 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 you know I don't know of very many people that have met her that don't say she is just the sweetest little girl, she is just 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, you have few more years of experience and I came to you, what advice would you give me?

Matt: Probably to not treat her any different than any baby you know. 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, you did a good job. 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. Once we found, actually before we had a diagnosis, we started in with an early intervention program they have up here, and she still goes to therapies. We go to therapies several times a month, and like every other week and she does it all: physical, occupational, speech, feeding. They are always joking at the hospital that we should just move in there cause we are there all the time. And 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, like, find your community. And even though it's hard, try not to stress too much, and just try to enjoy your day-to-day. And to celebrate whatever milestone your child hits, whatever they do you make it a big deal because it is a big deal. And to love your kid, go ahead and make memories with them. We took her to Europe with us on a vacation that we went on with my family and she did great. A lot of people worry, "Oh, if I have kids, especially if they had disabilities, I'm not, 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, 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, thank you Tori for meeting with me briefly. Any closing words?

Tori: Just 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 of carrying the virus. And, I mean, it's something that I've learned about, and I want to spread awareness about because it is, I mean, she's kind of on the mild end, and there are kids out there with the same thing who have more struggles. It's kind of one of those things that you might feel guilty because it's like I could prevent this, but I didn't know anything about it. So, I wish the doctors would be open and share with their patients. I also read a really great quote, and I can't remember who it was, but it 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." So I guess it's just celebrate life, help each other out and be kind. I guess that's what I've learned from having a child with a disability. I feel like it's helping me become more patient, and more maybe aware of that face that everybody has struggles, and just to 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, friends?

Tori: I mean, 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 she, again, she just brings joy wherever she is, you know. Her teachers, people we meet, she's just a happy little girl. And make her laugh, and meeting people who know sign language and so some signs with her. I don't know, she just has a way of bringing people together and bringing a smile to their face. And you know she learned how to crawl at my parents' house back in Virginia, and we are all like, "Yeah, big party." So, kind of turn everything into like a big party.

Matt: With my family, like I said I'm the youngest, so she has a lot of older cousins, and just how caring they are for her. I mean, the older ones don't pay too much attention, but they don't pay too much attention to any of the younger kids, but the younger ones, they come to her and try to play with her even though she can't move around. And so, it's been really nice, you know. 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 mama. You know, every time we get to go down and see her, we ask, "Do you want to see mama?" And she just, you know, gets her huge grin on her face, so I bet she has had a big impact on my family as well.

Gerald: Terrific.

Tori: It's great to see other people love your kids, and to see your family love your kid, even your child who is a little different, is heat warming, 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.