An Orange Socks Story: Stacy and Terry- Cru Di Chat

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 was so glad for the opportunity of speaking with Stacy and Terry about life with twin girls Sydney and Logan who have Cru Di Chat syndrome. I'd never met anyone with that syndrome before, it's relatively rare and occurs in 1 in 20,000-50,000 people. Terry explains the diagnosis.

Terry: The right arm of the fifth chromosome is missing, and there's rings.

Stacy: There's rings around each chromosome and there's a few rings missing from the right arm of the fifth chromosome in each girl. That is what causes the Cru Di Chat. Different variances, each ring does something in the body, and then it's all throughout the body. What it usually is, is low muscle tone and mental delays.

Gerald: Stacy tells of their family of four daughters and what their typical day to day routine is like.

Stacy: They would go to school and went through age 21, and now they are home except for some special programs. They do get to go on outings with different people. An organization right now being the RISE corporation that they really enjoy. Then they are just home with me and we run around and go to the store and watch TV, and Logan plays on the computer quite a lot, surfs the computer and Sydney loves being a mermaid and spends many hours in the bath tub, as long as I keep heating it up.

Gerald: Stacy and Terry remember finding out about the diagnosis and each of their paths toward working through their grief until they found acceptance.

Terry: When they were born, I was in between jobs and we were in that six-month waiting period for the pregnancy so we didn't have an ultrasound. We were expecting an eight-pound baby and Sydney came out at about three pounds first and a midwife said, "What a peanut," and put the heart monitor back on Stacy's Belly and said, "Another heartbeat, there is another baby in there!" So then five-pound Logan came out. So, it was eight pounds just in two packages that we didn't know about. So, we didn't know for a year until they were slowly developing and our family physician sent us to OHSU, Oregon Health Sciences University, the University of Oregon, in Eugene and that's when we found out. We were in shock, we had no idea, we weren't prefaced at all and he just said, "Well, your daughters are retarded because...." and our mouths dropped and we didn't know how to react. It took me a little longer to accept it than Stacy. I remember her telling me, "Look, they are still Sydney and Logan, they haven't changed. It's just how we are looking at them that's changed." And I've never forgotten that. She just snapped out of it, but it did take me a little bit longer to do that.

Stacy: They were three weeks early so we heard about premature children so we just thought, "Well, they are behind." Then our doctor said, "You know, I want you to have them checked out because their heads were measuring smaller." And so, we took them in and did a blood test, and then when he told us, he said, "It's not Down syndrome, but it's like that. It's a syndrome." I remember looking at them and thinking, "There can't be anything wrong with them." Which now I know there was nothing wrong with them, it was just my thinking. We were just in shock. We had made all these plans for them and their lives. I can only relate it to something similar to death. Because it was the death of a dream that you had made for them. Especially being twins, we had heard all of these stories of twins doing things. We get very emotional about our girls. It took a while because, like I said, it was like a death of a dream of what we had pictured for them. We just didn't know the future and all we knew was that mental retardation was not quite the thing you'd want for your children. Maybe they'd have a hard time in life, or they'd be mocked or scorned. That's all in the beginning because you just don't know and it's very scary because these are your babies.

Gerald: Stacy loves to talk about her daughters' fun personalities and their likes.

Stacy: In our cases, they like everything a non-delayed child would. Sydney and Logan have a disability that is visible. I think we all have our disabilities, but they don't show. Theirs is just visible, they love people, and us. They love to watch TV, they like food, they like to go to the park. They love being around their friends. People with disabilities in general, they can tell, they know that we call them their kindred spirits. Like at the Special Olympics and stuff, they love going to that, it just thrills them. They are not keen on participating, but they love to watch and just be around their peers.

Gerald: Terry shares with us what really helped him overcome his grief and to get to a more productive space regarding his daughters' lives.

Terry: It probably took me a couple of years, but we are Christian. I think our Christian faith is how we got through it. God doesn't make mistakes. They needed us; they needed their dad they needed their mom. Once you realize that, "Okay, time to move on."

Gerald: Nevertheless, personal journeys are always different. Stacy shares hers.

Stacy: They are a blessing. Well, they were a blessing even from the beginning, because they are my children. I just had to adjust to the thought that they might have a different path than I had expected for them. That I was walking their path, they weren't walking mom. Now they are Sydney and Logan. They are actually easier to raise than my two other daughters who are non-delayed.

Gerald: The couple offers their guidance in what anyone may need to know in dealing with a diagnosis of Cru Di Chat.

Stacy: Read all the information you can. Although it might not all be pertaining to your child, because everybody is on a spectrum so to speak, but at least it gives you some control. Treat your child like you don't know anything's different. Just love them the way they are.

Gerald: Vulnerability. Stacy admits that she was concerned with how her girls would be treated by society and at school.

Stacy: When they were in school my concern was watching other children look at them, maybe mistreating them. That was a huge concern of mine, it consumed me sometimes. I didn't want anybody mistreating my daughters because their classrooms were regular ones at school. But you find it's really good for the kids, and the school, for those students to be in there, to be around them. It does help them, I believe, longer in life. The outcome for the students to be more considerate and sincere. For her to get peer tutors is scary, you just don't want your children to be hurt. Maybe some things they don't even understand, which is fine.

Gerald: Raising children with special needs comes with bright joys, but also challenges. Terry shares his difficulties and points to some of the greatest joys that have touched him.

Terry: Mainly living together, we have older sister Bree who's also a guardian in case something happens with us. She's momma hen and very protective of them. I think I said in the last couple of months to Stacy, "You know, she and I just can't even go for a walk. One of us has to be here, somebody has to be here." You know, that is something that I hear from other people, "Can't you just come over and visit?" Well, they will have a meltdown, potentially, if there is a lot of people. We had to quit going to church just because of that. We would be there five minutes and have to leave. Everyone has problems, you just have to adjust. This is just what we have to deal with. They are worth it. I would give up anything. I love coming home, and when I travel a lot Sydney and Logan are just, "Dad!" And I still get that, at my age, I'm pretty lucky. That's pretty cool, you know, because usually they grow up and they leave and during the day I'm sitting back and Stacy has created a kind of man-cave back there for me to watch my sports. And Sydney especially, but both of them, I don't know how many times a day, 20-30 times a day just to make sure I'm there. Just to say, "Hi," and then come back. I might get 20 hugs a day from especially Sydney. You know, it's pretty cool.

Gerald: Stacy offers her point of view of the challenges and joys in this journey for her.

Stacy: I don't view anything as a challenge or a chore, this is my life. These are my kids. Maybe the only thing that I would like different would be to spend a little bit more time with my other two daughters individually and my husband. Just a little, because I really have to make sure they are taken care of. But that's not a problem, that would be the only thing. Just to have a little bit more freedom, just to get up and go and do this and that, but it's no biggie. I love them very much and I can't imagine my life without them in my family.

Gerald: The couple talks about the impact that Sydney and Logan have had on their other two children.

Terry: Well, for Bree crying along with mom right now, she loves them so much too. Her younger sister Trevi, whose personality is a little bit different. She used to wonder when she was two or three why she would have to live with them. To now, she loves them just as much. She's 27, and you have compassion. You just grow up with a compassion and I'm glad my kids have done that with their sisters. Then Bree is the mother of our nine-year-old grandson. Just the compassion that he has grown up with for his aunts. I remember saying one time that people might look at them funny, or might be mean to them. He just looked at me like, "Poppy, why would they be mean to them?" So back to your question before with your daughter, I think the younger generation that's coming up, I don't think it's going to be a problem for them. They have grown up with the integration, they are just different.

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