Orange Socks Story – Celeste: Fragile X syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I am very grateful to Celeste who took the time for an Orange Socks interview about her son, Tyson, who has Fragile X syndrome. I learned from Celeste that the gene wasn't discovered until 1989, and that a third of the people on the autism spectrum have Fragile X syndrome. Tyson is the youngest of three children and is now 21. I am so happy Celeste was willing to share her experiences over the last 21 years.

Gerald: Celeste, thank you so much for taking the time to meet with me for an Orange Socks interview about your son, Tyson, who has Fragile X syndrome.

Celeste: That is correct.

Gerald: Is it called Fragile X syndrome or just Fragile X?

Celeste: Fragile X syndrome.

Gerald: When did you find out that Tyson had that syndrome?

Celeste: I found out during the pregnancy.

Gerald: About how far along were you?

Celeste: I found out that he had Fragile X at 25 weeks. I had an amniocentesis at 15 weeks, so we had 10 weeks of waiting for the results.

Gerald: Whoa.

Celeste: Yeah.

Gerald: I think they are a little faster now, because he's 21, did you say?

Celeste: He will be 21.

Celeste: It took so long at the time, taking the amniotic fluid, they had to grow the cells to a certain point, and for some reason, they had to start over with his so it took a little bit longer to get to the point where they could analyze the DNA. If I had waited, which was an option, until he was born and then examining cord blood, it would have taken about a week.

Gerald: What advice did your attending physicians or different doctors who worked with you give you at that time?

Celeste: At that time, I went to Primary Care to have the amnio done, and they were basically just doing the procedure. I had been in contact with a Dr. Hagerman in Denver at the time, who is a world-renowned specialist with Fragile X syndrome. She and her genetic counselor, Louise, were the ones that saw me through the whole thing. They told me that if the child was a male, there would be a chance that he would either be affected or not affected. They clearly laid out a lot of the symptoms, and like anything, there's a range of symptoms, but they pretty much laid it out for me and tried to prepare me as much as possible. He did have Fragile X syndrome, so when I went for the amnio at 15 weeks, they weren't sure if they could determine the gender, they were just going to pull the fluid. We found out during that ultrasound during that amniocentesis that he was a boy, there was no mistake. They didn't know if they would be able to tell, but we knew he was a boy. Mentally knowing he was a boy, I knew it would either be an affected male or a non-affected male, so that was pretty overwhelming. With the help of the specialists in Denver at the time, it did help me to understand what my husband and I might be facing.

Gerald: So, Celeste, did anybody at that time counsel you to abort the pregnancy?

Celeste: I don't know if they counseled me to do that, but they let me know that was an option.

Gerald: Okay.

Celeste: I went in knowing when I became pregnant, because I knew that I was a carrier for Fragile X. We found out after my second child that I was a carrier, and either way I would keep the pregnancy.

Gerald: Tell me, what has been the hard part, the struggles? You've had 21 years of life with Tyson, and with Fragile X syndrome, what have been the hard parts for you?

Celeste: The hard parts would be being able to maintain a normal life with a child who has a condition such that he may get anxious or overwhelmed in different situations and learning how to adapt to his needs during those times. Once we learned to adapt, that's gotten easier. You know where that's not going to work, where it's too overwhelming, or figuring out what to do to help him be comfortable in a public situation. Another hard part would probably be toilet training, he's still not toilet-trained, and that's just something we got used to.

Gerald: So, with his Fragile X, he would have an intellectual disability?

Celeste: Yes.

Gerald: Okay.

Celeste: He can understand a lot of things, and he's very smart, but I don't know about the toilet training. I think that we are getting closer to starting it. Life with Tyson is like having a toddler. You can't leave him alone because he gets into things like a toddler would. He'll wake up in the middle of the night and take something out of the fridge that you may be saving and eat it. Those are some of the challenges I would say on a day-to-day basis. One of the things that being Tyson's mom has taught me is how to deal with negative people who don't understand children with special needs and go after them in a hurtful way. It has caused me to be a fighter for him and be his voice when he didn't have a voice, to stand up for him and be his advocate. It has made me learn that I had something in me that I didn't know I had, because I've been able to be his advocate and stand up for him in situations where he needed me to.

Gerald: Great. Awesome, does he have any medical issues that have caused concern?

Celeste: Luckily, he is super healthy, never a seizure, other than the normal colds and flu, he has been very healthy.

Gerald: Easier question, what have been the joys?

Celeste: The joys have been a lot. He is very caring and loving to us, and he is a very genuine child. He is always worried about different things in the house and where siblings are or where one of his parents is, and he asks questions like that. The overall joy is that he is so genuine and loving and sees the world very simply. His needs are very simple for his happiness.

Gerald: What impact has he made on your family, his two older siblings as well as your extended family?

Celeste: We always have to consider when we go on a trip or go anywhere what Tyson's needs are. His siblings have just learned to adapt to that, and they are used to that. We can't just pick up and go like to an amusement park as he has a hard time with that kind of stimulus. But really, we have tried to adapt to Tyson's needs, but also just have him adapt to our lifestyle and what we like to do. For example, my son played baseball, and Tyson learned to love to sit and watch baseball games, he really did like it. He learned to love camping because we love camping a lot. He is really good when we go out to eat, and he does really well there. We've tried to incorporate him into our daily life, because I felt like early on, it was important that we be able to have a life, but listen to his needs too.

Gerald: Sure.

Celeste: I think that my two older kids have done a remarkable job in understanding that.

Gerald: If I were to come to you having received a diagnosis in utero at 25 weeks that I've got a kid with Fragile X syndrome, what advice would you give me?

Celeste: The advice that I would give that person is to certainly mourn the fact that you're going to have a child who is not normal in the world so to speak, so mourn that. It's not a bad thing go through that grieving process, and then once you've been able to go through that grieving process, embrace it and accept it, read about it and talk to other families, and always ask questions. Try to look at it as this wonderful thing instead of something that's negative. That's what I would tell someone who is expecting. Know that every child is different, and they are just going to have to take it a day at a time and really learn their child and what makes their child unique with that syndrome while also being able to talk to others in that situation. I had the experience of knowing someone who had an older brother who was diagnosed with Fragile X in his late 30s, I knew that I loved him for him. We didn't know what his diagnosis was. When he was younger, we thought maybe he had brain trauma at birth or something, but I realized that they are people and individuals, and you just have to learn to accept that individual for who that individual is. Once you do that, it's okay. It's a different challenge, and it's not the challenge you were expecting when you're going to have a baby, but it's just a different challenge. That doesn't mean it's bad, it's just different, and that's what got me through the pregnancy and the leading up to his birth, knowing that whatever lay ahead, he was going to be born and it was going to be okay, that we'd deal with it as we go.

Gerald: Any last words?

Celeste: It has been a wonderful gift and challenge at the same time, and we are still going through that challenge, but I really wouldn't change it for anything. He's a wonderful boy.

Gerald: Wonderful, thank you.

Celeste: Thank you.