An Orange Socks Story- Maria: Trisomy 18- Edwards Syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was grateful that Maria sat with me for an Orange Socks interview. Maria is currently pregnant with a little girl with Trisomy 18 or Edwards syndrome, and is scheduled for delivery in three weeks. Maria received this diagnosis at her 10-week prenatal check-up. Despite being strongly encouraged to abort her baby, Maria has marshaled on. In fact, she moved to another state and community where all the available medical professionals can be on hand for the delivery.

Gerald: Maria, tell me, when did you find out you that you were carrying a child who had some issues?

Maria: At 10 weeks of gestation.

Gerald: Okay, tell me about that.

Maria: I was prompted to do cell DNA testing because of my age. I did that the same day I went to see the high-risk doctor. I got the call that I needed to come into the office because my test results were in. She saw me immediately and let me know what they were looking for, and told me that I had tested positive for something called Trisomy 18, which is a chromosomal abnormality. It's genetic and happens at conception. I was told that there's nothing they can do to reverse it, fix it or help it. They don't even know if it was something that came from mom or dad, it just happens. It was nothing I did or didn't do, take or didn't take, it's just one of those things that happens. About 1 in every 5,000 women are diagnosed with this, and I was one of the 5,000.

Gerald: What were your thoughts about this when you got the diagnosis? How did you feel?

Maria: Well, first I wanted to know what it is, and what does that mean. I was asked if I wanted to know the sex, and I said yes. I knew then I was having a girl, so I said, "Okay, what does this mean for my daughter?" I was told at that time that this condition is incompatible with life. Typically, women miscarry because our bodies don't do well adjusting to chromosomal issues. If I was lucky enough to make it past my 13 weeks, the baby I was carrying would more than likely be stillborn at the second or third trimester. And that because of my age, she really encouraged me to terminate if I wanted to have any more children. "There really was no hope for her," is what I was told immediately. I said, "What are the statistics as to how accurate your tests are?" They said they were 98 percent accurate, and I said, "Okay, so there's still a 2 percent chance that you could be wrong. I questioned everything. The validity of the test, where did it come from and how long have they been using it. I just needed to know who came up with this test. She gave me all of the answers. It had been used in Europe for many years and used to be very expensive, $10,000 to take this test. Now it was being offered in the United States, and the last couple of years is when they started doing it. At that point, I just had to process that she's got this genetic disorder. Then she recommended that I do an amniocentesis to confirm, and then they'd be able to pinpoint more what organs would be affected, and they would really be able to say 100 percent that she has Trisomy 18. I declined because I knew that if I had the amniocentesis, I would be risking going into pre-term labor. We figured that with these odds of 1 in 5,000, I was also told that 1 in every 1,000 women goes in to pre-term labor. I've already beaten some pretty high odds, so I said no. For months and months, I was prompted to have an amniocentesis, and I finally just had to say, "Enough. I'm not doing that to my daughter. She has a beating heart, and as long as that heart is beating, my answer is no." I just continued to fight for that. She has a heart that's beating, and it was always within normal range, so to me, that was my God telling me the fight was just beginning.

Gerald: And now you are about to deliver.

Maria: I am.

Gerald: In just a matter of a week or two, right?

Maria: Three weeks. Tomorrow I will be at 36 weeks. Part of the story is that in the state where I reside, we don't have major medical, and there isn't a NICU. So I would ask all the obvious questions, "Should I be somewhere with a NICU? Should I be somewhere where there is major medical? What would we do if my daughter is in distress? Would we do a C-section?" There was never any hope offered, nothing other than you're prolonging the inevitable. We are just going to let it take its course was the attitude. I heard a story about a woman who was Catholic, like myself, who went 32 weeks and the baby was stillborn. There was never any hope for her life, though she had a beating heart. She continued to grow, she weighs 5 pounds 2 ounces today, and her heart rate was at 144 this Wednesday. She is still fighting. She is not stillborn, and I didn't miscarry. I had to be her biggest advocate. This diagnosis is looked upon as hopeless. The medical community, for the most part, doesn't look at her as a person, they look at her as a diagnosis. I'm fighting some pretty big odds according to them, which is what prompted me to start looking elsewhere, to get out of that town and look elsewhere to find those who will listen to me, who will help me to do everything to get better care and better testing, and to prepare for her life regardless of what that looks like. I'm aware that I may only get 15 minutes. I'm aware that it may be an hour, days, maybe weeks. I was told that if she makes it past the delivery, she won't make it to a year, that these babies typically don't make it to a year. As was suggested, I've done a palliative care program here, and I've had to prepare.

Gerald: So you moved out of state to come to where you are now.

Maria: To where I am now.

Gerald: To where you are now.

Maria: I've been here as of 12 days ago. It has been awesome here, because this is where they were willing to fight for her. This is where the doctors were willing to open doors for me. After my first trimester, I found out at 10 weeks, then I was at 12 weeks, and I wasn't getting anything positive, so I started making my own phone calls to doctors' offices and insurance companies. What would they pay for, what would they not pay for, can I just show up and say here's my insurance information, and will you see me? It took a lot of phone calls and a lot of research to find high-risk pregnancies, and I did a lot of praying that God would open a door for me somewhere else. When I would ask, "What if I go full-term and she is in distress? Would you do an emergency C-section?" I was told, "No, we would probably just let it take its course." I just couldn't live with that, "So, you're going to let my baby die? You're not even going to try?" I found another doctor here who agreed to see me once a month as long as I was seeing my other doctor every other week to check her heart. I agreed to that. I started traveling, so I asked the doctor here what would I do if I went into pre-term labor. What does this doctor need to do there? They need to get you to somewhere with major medical because of your wishes for your baby's serenity. I went back and told her that this is what the doctor suggests. "Well, you need to consider that if you do go into labor and we can't stop it, having a C-section is major surgery. Putting yourself through that surgery for a baby who is not going to make it is a lot on your body." That was pitched to me, and I thought "That's okay. I'll go through it, whatever it takes." "If you deliver her and she is in distress and we have to airlift her, you won't be able to go with her, and a baby with Trisomy 18 will not survive before 39 weeks, so you need to consider if you want her airlifted. You won't be able to go until you're better. It's 3 ½ hours away by car, and you need to really consider keeping her here with you to let her pass." All those reasons told me to get out of this town and go somewhere else, fight somewhere else, which is what led me here.

Gerald: You have all that here, so if they have to do a C-section or whatever needs be, you can do it. You have all the medical facilities around you to accomplish your wishes.

Maria: Correct.

Gerald: That is admirable for you, that you've advocated for your daughter to that degree. Good for you. You can't gaze into the future, we don't know what's going to happen, and you are prepared for a short time with her. Maybe you're even prepared for the chance that she doesn't even make it. I don't know, but being prepared, maybe she lives for who knows how long.

Maria: Right.

Gerald: It's tough to prepare for the future. What's your biggest fear?

Maria: Truthfully, that medically, somebody else will make a decision for me that I don't agree with. I may make the wrong decision. I ask God daily to please give me clarity when it is no longer about her and it's about me, if it comes down to the point where she's just not thriving and is suffering, that I would know when to say enough is enough and to let my daughter go if that's what it comes down to.

Gerald: What's your biggest hope?

Maria: That God will give me a miracle, that He will give me time with her.

Gerald: If I were to come to you having just found out that I had the same sort of diagnosis with a child at 10 weeks and not sure what to do, what advice would you give me?

Maria: The advice I would give you is to fight for your baby no matter what. No disrespect to the medical community, however, they are medical practitioners, they are not God. And my God tells me that He has the final say. I would just say fight no matter what. Ask questions, as there isn't a silly question. If in your heart and in your gut you feel that you're not getting the answers that you need for your child's life, and that baby has a beating heart, then you make another phone call. If they don't pick up, you make another phone call, and if they don't pick up or don't call back, call back again. Don't give up, don't quit. People get busy and life happens even at a doctor's office. If you can, get past the receptionist to get to the manager of that office, explain your situation, ask for copies of your test results and start faxing and emailing away. Do whatever you have to do to get somebody else to take a look at those test results if you have the resources and if you have a way. If you don't, ask God, "How am I going to make this possible?" I've never asked God why, I've always asked him how am I going to do this, just how, God?

Gerald: It seems like you've experienced some miracles already because you're here.

Maria: Absolutely.

Gerald: You are in a different place with all the things that you would hope for medically to help you daughter.

Maria: Correct. We're doing ultrasounds. She has congenital heart disease so she already has a cardiologist. I see a genetic counselor as my lab works specifically said genetic counseling is recommended, yet never once was it offered, I sought that myself. It was there in those nice little notes. I only got the first page, so I asked for all the pages. They said that the first page is all you need. There were seven pages, so ask for everything. It may not make sense to you, but it will make sense to somebody else. Look for those notes that say otherwise.

Gerald: Maria, thank you for taking the time to talk with me. This is an anxious time. We're not sure what's going to happen in a handful of weeks.

Maria: Right.

Gerald: It's just two three weeks at the most, right? Then you'll have a baby.

Maria: I will.

Gerald: That's a wonderful thing. Any final remarks that you'd like to make?

Maria: I would just like to thank you for the opportunity for allowing me to share my life and my experience, and for being part of my journey. It has definitely been a challenging time, but I don't regret any of it. There isn't a day that goes by when I have a regret or a thought of maybe I shouldn't have done this. On the contrary, I feel her moving and I feel her hiccupping. She is my daughter, and she has a name, Serenity Grace. She is still a person, and this little life inside of me is still fighting. I would just say that there are absolutely no regrets. It has been hard, but absolutely no regrets.

Gerald: Thank you.