An Orange Socks Story – Erika: Microcephaly

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was grateful to Erika for taking the time for an Orange Socks interview about her daughter, Erilyn. During a six-month prenatal checkup, Erilyn was diagnosed with microcephaly. The medical professionals pressured Erika to abort Erilyn, predicting dire circumstances. Despite those warnings, Erika chose to have Erilyn, and while she does have microcephaly, she was nothing like predicted. She is now a beautiful, sweet and delightful eight-year-old who brings great joy to Erika and all those she associates with.

Gerald: So, Erika, when did you find out Erilyn had microcephaly?

Erika: I was six months pregnant when we found out that Erilyn was going to have microcephaly, and I remember that day perfectly. It was supposed to be a super exciting appointment for us, the one with the 3D sonograms so you can kind of see the profile and get a really good picture of the baby, and we were really excited. We went in that day, looking forward to it, and then while we were getting the sonogram done, she was taking longer than normal. We kind of knew something was going on as she was gone for a long time. We finally went to the exam room, waiting for our doctor to come in, which took another 30 minutes which was kind of unusual. When she walked in, the look that she had on her face was a look that I would never forget. She looked scared, which terrified me. I was 15 years old when I was pregnant with Erilyn, and my mom was with me and so was Erilyn's dad, and automatically we knew something was wrong. She explained that Erilyn's head and brain were measuring smaller than normal through the sonogram, and that it was something called microcephaly, which was obviously something that we had never heard of. She explained pretty flat-out that I had the option to abort my pregnancy even though I was already at six months, and if I wanted, she could refer us to a specialist in San Antonio the very next day. She gave us a second to think about those options and just walked out. We talked about it, of course. I busted out in tears, you never think that will happen to you until it does. We decided to go to San Antonio and see what that doctor had to say. We went to San Antonio the next day, and sure enough, they did another sonogram and explained about microcephaly, that it was her brain and head that were measuring smaller than normal, and that it was going to cause her to be mentally delayed. They thought that she would be pretty much like a vegetable if she even lived past birth. She would never be able to walk or talk or do anything on her own, and they even told us that they showed my mom and her dad a picture of a baby who had really bad deformities on the face, and they said that this is what your baby is going to look like. My mom didn't even let me look at the picture, she said it was terrible. They said that this is what your baby will look like if you do continue to go through with the pregnancy, and they just left us with that. We came back home and talked through all our options. Which wasn't very hard, I mean, we knew we wanted to go on with the pregnancy, it was just all the things that were to come. I just wasn't sure what to think of it since we were so young.

Gerald: It seems like they put a lot of pressure on you to abort her even at six months.

Erika: Yes, they did, and I kept saying that I'm already this far along, and I can feel her moving every single day. I couldn't imagine just getting rid of her just like nothing. There is always that "What if?" I couldn't imagine getting rid of her, and what if she comes out perfectly fine? I couldn't not give her that chance to show us what she is capable of doing.

Gerald: Obviously, you had her, so describe when she was born.

Erika: That day was nerve-wracking. We had many friends and family there. I had to have her by C-section, of course, so we were very nervous, and when I went back, I just remember praying the whole entire time. Just praying and praying and hoping that everything would come out okay. I wanted a bald baby, I didn’t want her to have hair, and I remember them pulling her out and saying that she has a head full of hair, she has a lot of hair. I saw her face and saw that everything was perfect. She looked perfect, and she had the cutest little nose, and everything was normal. They took her out and after that, I honestly don’t remember anything else. I was on medication, and I fell asleep for hours. I remember waking up constantly to different people in the recovery room, and I asked, “What are y’all doing, just watching me sleep?” They said that everything is okay, don’t worry, she’s fine and she’s perfect.

Gerald: Isn’t that great? What have been some of the challenges that you have experienced so far with her?

Erika: I would say the delays, she is non-verbal, and she isn’t potty-trained.

Gerald: How old is she now?

Erika: She is eight years old.

Gerald: Okay.

Erika: I still pretty much have to do everything for her. I still have to bathe her, I still have to feed her and change her. I would say that is a challenge, having to deal with everything like that. There are emotions that come a long with it. I feel like every other day I say I’m a hot mess, like my emotions are everywhere all the time, and sometimes just thinking ahead is what overwhelms me, thinking of her future. I don’t know where she is going to be at this time. I can’t say, “You know she is going to be doing this,” because I don’t know, and God willing, she will be moving forward with everything. I would say the challenges are just having to deal with the emotions that come along with being a parent of a special-needs child. There are days when I have no energy, and I know I have to feed her, and I have to bathe her and do everything else, especially when she is not very helpful, so I would say those are the challenges.

Gerald: What is a typical day like for you?

Erika: Right now I am working as a part-time waitress. Erilyn goes to school the full day, which she loves. She absolutely loves being around other kids. She does attend physical therapy, occupational therapy, speech therapy and food school therapy, so we have a pretty full week besides school. She has appointments throughout the whole week, and she does see a specialist in neurology genetics, but that’s just occasionally. We have to travel out of town which we are totally fine with because the doctors and the therapists we work with are amazing, and we are so thankful for them. Other than that, she likes to just hangout, and she loves watching her movies and snacking on all kind of junk food that she probably shouldn’t have. That is pretty much our full day.

Gerald: What are the joys?

Erika: Just everything, she is so amazing every day. I could be having the hardest day and be in the worst mood, and she will come up to me and give me a kiss and just smile at me and look at me in the eyes, and that is enough for me to snap out of it and realize how blessed we are. She is always giving kisses, that’s her favorite thing to do. She’s just such a joy to have in our lives, and I feel everyone who comes across Erilyn is just touched by her, and they think she is the sweetest thing, which she definitely is.

Gerald: You know that leads me to my next question as to what kind of impact she has made on your family and your extended family.

Erika: I feel like we are all motivated by Erilyn. She makes us all want to be the best that we can be. Just to appreciate everything and not to take anything for granted, especially life, which sometimes is hard for us. She is just such a joy to have, and we couldn’t imagine our lives without her. This is our life, and we love it, and we wouldn’t change it for anything.

Gerald: If I were to come to you for advice and say that we just received a diagnosis that our baby had microcephaly in utero, what advice would you give me?

Erika: Have hope and have faith more than anything, even when you want to question God. I know other people have their own beliefs, which I respect, but I just left everything in His hands. My favorite thing to say is that I know He would never put us through anything that we couldn't handle. This is meant to happen; she was meant to be put in our lives. I would just tell them to keep their faith and to know that they are not alone, that's the number-one thing. When we found out, I didn't know anybody or any other families, and what has really helped is reaching out to other families. I feel like I have known them forever, and I haven't even met some of them in person. Just know that you are not alone, that there is always hope, there are a lot of different resources and programs for them, and just have faith in your baby and know that God will do everything in His time.

Gerald: Any regrets?

Erika: No, none.

Gerald: That's great Thank you.