An Orange Socks Story – Miriellys and Alex: Patau syndrome (Trisomy 13)

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: What a pleasure it was for me to meet with Miriellys and Alex to talk about their daughter, Aerilyn, who has Trisomy 13 or Patau syndrome, a very rare chromosome abnormality. I enjoyed meeting Aerilyn, what a beautiful and precious little girl. She occupies what used to be the dining room in the family home to accommodate her special bed and all of her equipment and supplies. Aerilyn is so loved by her parents, and I appreciated their candor and learning their wonderful story. When did you find out that your baby had issues?

Miriellys: Everything was pretty good with our pregnancy. I had no morning sickness. I had no issues. We were anticipating the day of the sonogram where we were going to find out the gender of the baby, so we were excited about that. We were kind of predicting, “Oh, it’s going to be a boy.” I knew, “It’s going to be a boy; it’s going to be a boy.” We were sitting there, and the technician was doing the sonogram, and she's checking and asking questions and repeating some of the questions like, "Have you taken any medication?" No. "Are you a smoker?" No. She grabbed the paperwork and walked out of the room. Before she walked out of the room, we asked, "Well, what's the baby's gender?" She ran back to the machine and looked, moved around and said, "Oh, it’s a girl!" Then she walked out of the room. We both got emotional, I was crying, “Oh, we're going to have a girl. We have the boy, and now we have the girl.” Then the doctor walked in and the whole mood of the room changed, because she was serious and had the paperwork in front of her. The first thing she asked me was, "Do you know what a cleft lip and cleft palate is?" I started getting very emotional, and I started crying and saying, "Yes, I do." She said, "There are many reasons why a child has a cleft lip and palate, we have to do an emergency amniocentesis." They did that, and then the results came in and that's when they told me that Aerilyn was going to be Trisomy 13. That was her diagnosis. Our life was pretty much kind of like we hit a wall. It was just really intense to get a diagnosis that I already knew some of the problems of in my own family, and the extremes of where Trisomy 13 could go. We have children in our family who have passed away from that diagnosis, and then we have children who are currently living, so we weren't sure where we were going with our own.

Alex: It hit her harder than it hit me because I thought, “Oh, it’s just a cosmetic issue. Don't worry about what the baby looks like, we can always fix that with surgery or whatever." That's what I thought until she explained to me what it was, and I was like, "Oh, okay." That's when it hit.

Gerald: So, tell me about how you felt when that hit?

Alex: When that hit, I felt everything all at one shot. I felt pain, fear and anger, and I was afraid of what was to come. I was trying to find something to be angry at, like to put blame on something. It wasn't until later that I realized that was a waste of an emotion, a waste of energy that I could use to direct to Aerilyn. I was trying to find something to be upset about. Like it’s genetics, or it’s her family's fault, but that's ridiculous. “Is it what we ate? Is it what led up to the pregnancy? How we lived our lifestyle that caused this? Is it, God? What did I do?” I was all over the place just trying to find something to put blame on. But then I realized that was just a waste of energy.

Miriellys: That was with me, too. I feel like when you don't understand something, you try and find something to blame. I was up more than the sadness; it was kind of like anger. “What did I do? Was there something that I did?” You try to find an answer to it where there is no answer. That is just the way it is. There's no control over life. You can't control life; it takes you into all different types of directions, and you have to just go with the flow and see what it leads up to.

Gerald: So, what advice did your doctor give you at that time?

Miriellys: We had a lot of resistance. I remember in the beginning, it seemed like, “Well, this is your diagnosis, and your child's quality of life is not going to be good. Her life expectancy is not going to be good. So, you have to kind of make a decision. We were six months into our pregnancy. I was just coming out of a sonogram where you could hear that her heartbeat was really strong, and they’re telling me she has a strong heartbeat. And then I have this doctor telling me I have to make a decision on whether or not I'm going to keep this child, and if I'm not, I have a timeline. I have a very short amount of time to make a decision. You kind of have an out-of-body experience when that happens because this is a decision that is not right. You shouldn't make the decision. No one should be put up against a wall to have to make a decision over somebody else's life. I think that was the hardest part out of the whole experience. That was the hardest for me. I think that's when I hit rock bottom, when we were faced with what we were going to do. Our faith is about life. Our faith is about God. Our faith is about hope, and to have that shaken where there's no hope, you almost kind of lose your faith at that moment. That was rock bottom for me.

Gerald: So obviously, you had the baby, you chose to carry the pregnancy. What's been the hardest part for you in having Aerilyn?

Alex: Adjusting. After Elias, everything was so easy, and being a dad was pretty easy. Being a dad for her is different. It's real challenging because with Elias, I can just bring him out, play some kind of ball game or watch some cartoons, and everything is good. With her, you have to figure it out. It's different. So, the challenging part is just trying to make her smile and laugh, which is pretty good because that’s one of the things she does a lot.

Gerald: So, tell me, what's been the hardest part for you as the mom?

Miriellys: For me, it’s...

Alex: Everything.

Miriellys: Everything. It seems like when you have a child with a disability, you're not just a mom anymore. You have to wear many hats. Now you're a therapist, you're a doctor, you're a nurse, you're an advocate, and you're a receptionist making and taking phone calls. It's challenging because sometimes you don't have time to feel what you're feeling. You have to muster it up and keep going through the day. So, if you're tired, there's no break, you just have to keep going. That's been the most challenging part, going from taking care of just myself and my small little family to now running, contacting 18 specialists, dealing with seven home nurses, dealing with three supply companies, and making sure that every month we have supplies ordered. Now it’s a whole world of things that you have to kind of manage and try to make sure that you get all the ducks in a row.

Gerald: What's the typical daily routine that you engage in?

Alex: Super busy with no break.

Miriellys: There's no break.

Alex: You need like three cups of coffee.

Miriellys: There’s no break, no break. You're constantly running. For us, just a typical day is for me to wake up in the morning and say, “Okay, who do I have to call today?” I have the medical supply companies that I have to call, and I have to call transportation because she has three appointments this week. I have to make sure all her doctors’ appointments and her referrals are up to date. I have to make sure that they have all the paperwork that they need and that I have all the paperwork I need for her. Also, managing seven home nurses is where all the supplies are. This is where the things are that she needs. Today she has a cough, she's congested, and she needs some suctioning.

Alex: You forgot about struggling with all of the companies that you call because they make it so difficult.

Miriellys: Oh, they make everything difficult, I sometimes feel like I'm doing my job and their job as well. They don't understand that if something is not done on their end, it affects us pretty badly. If her feeding company doesn't send out her feeding supplies for that month, I can't go to Wal-Mart or the supermarket and buy her over-the-counter foods. There is food that is specially made for her, for her feeding tube, that she tolerates. Things like that, extension supplies, a bunch of supplies. I now have to rearrange my house to fit into our lifestyle. My basement is full to the top of supplies that Aerilyn uses on a daily basis. I took out my dining room furniture to make her room, because her room is on the second floor, and we can't carry her up and down. To accommodate basically everything, all of the equipment and everything, is a lot of work. But I think when you love somebody, it just becomes part of what you have to do. It's just, it is what is. Tomorrow is another day, another full day of work, work, work. I start the beginning of the day running. The first thing I do is start making phone calls because the rest of the week needs to fall into place. I call it the stage, and you have to get all of your actors and stage prepped. It has to be all ready to go.

Alex: We'd rather have the extreme workload rather than the alternative.

Miriellys: It's true. When we had our first diagnosis with Aerilyn, my biggest prayer was, “Lord, please let me have this child.” You don’t know what it is to pray for a child’s life, and continue to pray. So, when you do have it, you want to cherish it, and every day is a grateful one. I'm just grateful that she's here. Because of the severity of their disability, many Trisomy 13 children have a short life. Aerilyn is going to be three at the end of this month, so it’s pretty extraordinary that we get this opportunity with her.

Gerald: On that line, tell me about the joys.

Miriellys: Oh, wow, I honestly feel that Aerilyn has magnified what joy is. With her, we're on a level like no one else. We're on a level where we appreciate every moment. We're on a level where we are grateful for every opportunity with her to be with our family and love. I've experienced so many different things with her. I was actually in surgery scrubs, with my little hair net and mask, in surgery with her. These were experiences I would have never had myself unless I were going to school. I was in the OR with her. The doctors respect me now, very different from the beginning of our journey when we had doctors telling us, "No, this is it, this is it, this is her diagnosis, and there's nothing you can do about it." Now they're asking me, "Mom, what do you want to do? You want to do this? You want to do that?" I answer, "You know what? Let's do this." Now the tables have kind of turned. They see how much we do for her, and how her care is very well-maintained. Like I said, she has all types of equipment that I had to fight insurance for. Many times they denied us, and I went ahead and kept pushing it. Her medical bed was almost a year of going back and forth fighting with insurance to get it. We finally got it. Her wheelchair was the same thing. They see this diagnosis that they've never heard before and don't understand, so automatically they say that you don't need something. That's not the case. She needs everything that she has.

Alex: Your question was the joys, right?

Gerald: The joys, yeah. Do you want to add to that?

Alex: The joys are waking up in the morning and hearing her sing. Not words of course, but she literally sings everyone awake in the morning, like, it’s time for everyone to wake up. You look at her, and she's just smiling and ready for the day. When she sees the sun, she even gets louder. That's a joy. She loves ceiling fans! It doesn't matter where we go, she loves fans at Lowe's, Home Depot, wherever. She doesn't have any control over her body, but she'll be looking for a fan. So, we thought, maybe it’s just objects that move. We've put her in front of objects that move, nothing. But a ceiling fan does the trick. The way she smiles when she sees it, chuckles and giggles and laughs, that is pure joy.

Miriellys: What she does for other people, too, is incredible, because people are really drawn to Aerilyn and inspired by her. I mean, I'm inspired by her, but to see other people be inspired by Aerilyn and have faith and be a little bit stronger than they were before is incredible, because she brings out such good in people. Everybody just wants to kind of be like her because she is so strong and so powerful.

Alex: Surprisingly, she brings a lot of happiness to people. We see a different side of people that we really don't see when they encounter her, which is pretty beautiful.

Gerald: You know, you're anticipating my next question, which is what impact has her life had on your immediate family as well as extended family, friends and neighbors?

Miriellys: I feel like from the moment that she was born, everybody was kind of rooting for her. They knew that if she can do this, as small as she is, that they can do anything. I've seen a lot of people being more open to having a struggle but trying to overcome it. Because if they see Aerilyn overcoming something, they can overcome it, too. They're inspired by her. People are more open to talking about their own issues, because even growing up 10 or 20 years back, it was taboo to talk about disabilities. There was something wrong with talking about disabilities, and now I feel like everybody is really comfortable with talking about her and the things we do day to day, because they see me going through it with her. It’s a great feeling to know that your child is bringing out so much good in someone else.

Alex: Her story has helped a lot of people at my job. We'll have a casual conversation, and they'll bring up something like, “Oh, I got a new kid,” or “This is what's going on with me and my kids,” and stuff like that. So, I'll offer them advice and then I tell them how it is living with a Trisomy baby, and when they see it from my perspective, they are like, “Wow, wait a second.” And the next day, they'll call me and say, "You know what, after that story you told me, Alex, I went home and everything I thought was an issue, wasn't really an issue, and I handled it just fine. Everything is great now." Just having her around and her story being told to other people, helps other people out with their kids. "I'm having so many issues," and then I give them some advice, and they hear it and it makes sense.

Miriellys: A lot of people kind of see what we go through day to day, and then they say to themselves, "We have nothing to complain about." They'll say, "You know, I see what you go through, and it makes me appreciate that we have it pretty good, that there's nothing really to complain about." Like if I'm not complaining, why should you? You know what I mean? I've seen a lot of people kind of appreciate their life and say there are greater struggles out there. I say that to myself, too. I meet a lot of other families online, and everyone has a different diagnosis. Some children are struggling more than others, and I say to myself that I'm so grateful that Aerilyn is who she is and how she is, and I shouldn't complain as it could be worse. So other people's stories are helping us out, too.

Gerald: That's great! So, if I were to come to you and say, "Hey, I just received a diagnosis that our baby has Trisomy 13,” what advice would you give to me, and let’s say I'm at 20 weeks or so?

Alex: I would say the usual, stay strong, stick with it, but I think the more important thing is to have faith, because your faith is going to be shaken a lot. My advice would be to keep faith your number-one priority. Because if you keep that faith, it will help you out in, the short term and in the long run. Yeah, that's pretty much it because that’s the strongest thing I have.

Miriellys: What advice I would give is hard. When you get a diagnosis, no one can compare it to that. When you get a diagnosis, something changes in you, you kind of feel that you’re lost. The best advice I can give is what I've done with Aerilyn, which is just trust in your baby. Let your baby lead the journey. They're more resilient than you think. They're going to teach you more things than you can teach them. Embrace the moment the way it is because there is nothing you can change except your attitude towards it. Your attitude must be trying to keep the faith. Your job is to love and support. Your job is to be a cheerleader. Your job is to make sure that they don't feel alone. That's how I've felt with Aerilyn. We couldn't do anything. We couldn't do much but just have faith. That's what I did; I was her cheerleader. I was there by her side in the NICU holding her hand, holding her close to my heart, kissing her, whispering positive things into her soul. I was telling her that she is strong and that whichever way this journey would take us, that I was proud to be her mom. The best advice that I would give is just let your child do its journey.

Gerald: And you've provided her with a wonderful loving home.

Miriellys: Thank you. She's brought so much into our life that I'm so grateful for every moment of it. It's just such a beautiful life. It’s okay that we're tired. You know you're exhausted, and there are a lot of struggles. There’s no changing that, but there’s the gift of being the most grateful that you could be, the gift of loving deeper than anything else. Aerilyn is non-verbal, but she and I still communicate on a different level. That's something that I would have never experienced with anybody else, but I experience it with her, this connection with your child like no other. I am so blessed and happy that our journey is the way that it is.

Gerald: Thank you for taking the time to meet with me and to tell your story, both of you, and sharing. It’s wonderful.

Miriellys: I'm glad that we're able to share her journey. I hope that it does go to someone who really needs it. Hopefully whatever words we say will influence someone to understand that the diagnosis is not the end of it. The diagnosis doesn't define your child. There's more to your child than just a label. I hope that reaches someone.