

## An Orange Socks Story- Ileana and Lorenzo: Microcephaly and Cerebral Palsy

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was so happy that Ileana and Lorenzo took the time for an Orange Socks interview. We talked about their beautiful daughter, Giselle, who has microcephaly and cerebral Palsy. They found out that Giselle had ventriculomegaly in utero at their 20-week pregnancy checkup. At that time, they were given the option of terminating the pregnancy, which they refused.

Gerald: Thank you both for meeting with me. I am really excited to talk with you. Ileana, tell me, when did you find out that your daughter had a condition or issue?

Ileana: We found out at the 20-week ultrasound. Giselle was actually a bit of a surprise to us, because at the time, we were on birth control, so it was an exciting time for us and a little bit of a shock. At the 20-week ultrasound, she had some abnormalities in her brain, and they told us that there was a large ventricle, which is referred to as ventriculomegaly. I was assured that it was mild and kind of insignificant, but they still asked me if I wanted to proceed with the pregnancy. I said of course, and the genetic testing came back fine. We didn't have anything, everything was within normal limits or was negative, so we thought we were in the clear. She was born on November 30 uneventfully. She was great, and we took her home and thought that the worst was behind us, so to speak. It wasn't until her four-month check-up that she was missing milestones, and the pediatrician made some comments. We got to the six-month follow-up, and she had made no progress. At that point, we were referred to early intervention. We started with what they said was precautionary. We started PT and OT, and the months just kept going, and that gap of where she needed to be and where she was kept kind of growing further apart. It has been more of a journey and adventure to get that diagnosis, because it wasn't just a simple appointment. It was all during different periods within her first two years of life. In terms of the microcephaly that was eventually diagnosed, they used to just tell me that she was falling off the curve, that her head was just a little bit smaller. They never actually told me that she had microcephaly, I actually came across that term looking at paperwork that said the referring diagnosis was microcephalic. I used my investigating skills on the internet and was shocked, because what you find online may not always be positive. That was that diagnosis, and then in terms of cerebral palsy, that actually just came six months ago after me pleading with them, we had got outside information was probably the cause of all the gross motor delay, so it was just a different experience each time. Global developmental delay was the diagnosis we got for the longest time, up until six months ago.

Gerald: Lorenzo, there were some issues, obviously, that were picked up in utero, but it sounds like there wasn't too much of a concern then, and then later on, you found out that there were some other issues. What have been your thoughts through this journey? How old is she now?

Ileana: She's three.

Gerald: Three years. What have been your thoughts over the past three years?

Lorenzo: Having a daughter with microcephaly, and now being diagnosed with cerebral palsy is a great opportunity to appreciate children with special needs. My mom adopted my youngest sibling who had Down syndrome. Looking at him at the age of 14, it's like he's special. What is Down syndrome? He's just as special as any child. I didn't see him as special, I just saw him as my little brother, so that transition had helped me prepare for Giselle. I was ready to be a father, to be there for my wife really, and it has been a blessing to have her in my life and appreciate children with special needs.

Gerald: Ileana, what have been the hardest things that you've had to deal with over the past three years?

Ileana: I think just finding my voice in this whole process. There was so much that was coming at us all the time, and it was difficult just being able to get through this new schedule. I have an older daughter, so balancing and making sure that everyone's needs were met when your youngest has needs that supersede, was a hard transition to find a balance while getting as much information as possible to be able to advocate for her. At the beginning, there was a lot of, "You need to go here, you need to do this, you need to do that." It was a lot of conflicting information that made me feel overwhelmed. I think the hardest thing in terms of the challenges that you face is just managing. There is a lot of anxiety that she has that has sometimes been difficult to overcome. Sleep for her has been a difficult thing, which kind of changes the dynamics of our home. Just getting onto solid ground has been the challenge that I've faced so far.

Gerald: What have been the joys?

Ileana: She's amazing. That little girl has grown my heart into just this unimaginable size. Because her delays are so significant, every little thing is magnified and is so important. As a family, we look at her, and we are all just amazed that she ate all of her food or she's crawling. Another thing is seeing her little personality develop. We hit a plateau of what she was doing for so long. I'm just so thankful that she's mine. She's my daughter, and I love her through and through. It has been an absolute blessing in spite of all the challenges. It has made it absolutely all worth it for sure.

Gerald: What have been your joys, Lorenzo?

Lorenzo: Seeing what Ileana's talking about, seeing her hit certain milestones and seeing her personality, her unique likes and dislikes come through. She has a personality. It has been great seeing her grow. I see her older sister, and I see her, and I see their own unique likes and dislikes. Her personality is just growing, and it's a big blessing and very comforting as she continues to hit milestones.

Gerald: Ileana, what has been the impact of her life on your immediate family, as well as extended family?

Ileana: In terms of our family, and as far as the relationship Giselle has with her grandparents, my mother and her husband have been phenomenal. They do not see the disability, they're just loving, and they want her to be included. In terms of her sister, that bond is just ridiculously adorable. Vienna is constantly this mini-advocate for her sister and she doesn't even know it. She thinks that Giselle's orthotics are just her cute boots, and she tells her friends that her little sister's going to ride the little yellow school bus. It's a beautiful thing to see that unfold. In terms of our friends and extended family, I think it has been a great opportunity to educate them and to bring awareness. Most of them had never really seen what disabilities are supposed to look like, or to check their perception of what it is. I know I did before I had Giselle, so it's been an awesome opportunity to use both the challenges and the strengths to help them redefine what disabilities are. That has been really awesome to see for sure.

Gerald: If I came up to you, Lorenzo, just coming back from a 20-week check-up where the physician has noticed some issues on the sonogram that might indicate microcephaly, what advice would you give me as a perspective parent?

Lorenzo: As a father, I've learned that it's important to discuss and understand their strengths and weaknesses. With Ileana, I had to be a better communicator and be up-front and honest, and say, "Let's get a game plan going." Through a learning curve on my part, looking back, I wish I would have better communicated what can I bring to the table, how can I help best, what my weaknesses are and how can we work through them so I can be a better father and a better husband. I didn't want her to feel that she didn't have my support, and so looking back, I wish I would have done a better job of communicating with her.

Gerald: Good advice. Ileana, what advice would you give me as a new parent?

Ileana: Looking back at those early days brings up a lot of emotion. I think the first thing I would probably do is just give you a big hug because I just know how hard that is to process. The biggest advice I would give is that it's okay to grieve and to feel hurt. I think I felt embarrassed that I felt that way, because I saw other families who were ahead of me, and they were finding this joy and this peace or this great perspective, and I felt like I was a bad parent because I felt that. Thinking about that, it is okay to feel that. My advice would be just not to stay there and to give yourself some grace. It takes time, and you have to go through that hard stuff. The only way to bind that perspective is to deeply seek community. Most of the solid, practical advice I've been given in this period of time has been from other parents. Seeing them and following their journey has reinforced my perspective that it's going to be okay, as well as helping me to redefine what okay means.

Gerald: You know you have to go through the process as a parent, accepting the hard parts and the joys. Is it worth it?

Ileana: Oh, absolutely, absolutely, absolutely.

Gerald: Yep. Lorenzo?

Lorenzo: I agree. It has been great just to see Giselle grow. She has brought something special into my life that I really appreciate, and I'm very thankful for.

Gerald: Any final thoughts?

Ileana: It's just an awesome opportunity to share our story. We've tried to do that, to bring as much hope as we can. There's such a stigma or perception of this false narrative of what disability is supposed to look like, that it's this awful tragic thing. In our experience, and in the experience of so many that we follow, it has produced something so amazing and so irreplaceable that it needs to be shared. Life doesn't have to be this perfect thing to still be wonderful and amazing. That's our biggest thing to share, that we're not a pity story, we are living a great life that just happens to look very different.

Gerald: Thank you both.

Ileana: Thank you.

Gerald: You guys are great.

Ileana: Thank you.

Lorenzo: Thank you.