An Orange Socks Story: Mercedes and Andy-Down Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I am your host, Dr. Gerald Nebeker. Today's episode is number 77. In this episode, Mercedes and Andy talk about their daughter, Sunflower, who has Down syndrome, who they adopted when she was just three days old. I know you are going to love hearing their story.

Gerald: Andy and Mercedes, thank you so much for taking the time to do an Orange Socks interview this evening about your daughter Sunflower, who has Down syndrome. You adopted Sunflower when she was three days old, and she is now four. Can you just describe your life prior to your adoption? what led you to adopting Sunflower?

Mercedes: A couple things, a couple big things. It was October, we had just been married. I think we were going into our third year of marriage, and we found out we were pregnant. We were surprised, it was a wonderful, glorious shock. In that first week of finding that out we actually had a miscarriage, it was the first time, obviously, that we had ever experienced anything like that, but it was the first time I experienced loss. Three months later, on New Year's Day, my brother passed away suddenly and unexpectedly, he was 21.

Gerald: Oh my.

Mercedes: And my world was shattered. It was right after that we had our miscarriage, that we also jumped into, "Well, maybe we do want to start a family." And it really started to get those wheels turning, but nothing was turning. And then my brother passed away. We were in recovery mode, and grieving. And it was a really, really hard year. And I just remember continually praying to God for hope, and for joy and to make this hurt go away. It was a tough year, to say the least. During that year, though, we went on a mission to Haiti. Specifically, to an orphanage of kiddos with cerebral palsy. There was about 40-something children there with cerebral palsy. We just kind of helped feed them. We partnered with the care takers there, and there were nine Haitian women who took care of 45 children with cerebral palsy. So, they were all laying there, and we just helped them out with the physical therapy, with feeding them, changing them, all that for two weeks. It was intense, and it was beautiful, and it was hard work. Andy and I were there, and it was just like, "Goodness, we would take home any of these kids in a heartbeat." Well, that kind of thought of adoption, which we had talked about previously getting married. Even that was going to be part of our life, it kind of just kept turning in my head. It was like, "Is this what we should be focusing on right now? And not trying to get pregnant?" And that feeling was not leaving me. I just felt like God continually putting that in my heart and in my mind, constantly. So, I decided to bring it up to Andy. And so, I said, "Hun, what do you think about adopting?" And he was like, "Okay." He was on board. It was a no brainer. And then I was like, "Well, what do you think about adopting a child with Down syndrome?" And again, he was like- surprising, well I guess it shouldn't be surprising, knowing him. He was like, "Okay, well, give me a day to think about it." He was positive, he was upbeat. And I was like, "Okay, fine." The next day, I bring it up again, and he was like, "Yeah, I think we should do it." And it was quick. And he was excited, and I almost, at that moment, was scared. Like, "Wait, what? We're really going to do it. You're on board, I'm on board. Okay, we're going to go for it." And it took off from there. And six months later, we were driving up to get our Sunflower. It was so fast.

Gerald: Wow, that is amazing. So, Andy, what were some of your fears? Or, what were some of your thoughts, maybe at that time, maybe when Mercedes said, "Hey, I think we should do this?"

Andy: At that moment, I was actually ready to just say yes. I think it was rather I didn't give my heart a chance to pause on this and think that this is good. Try not to be too ambitious. So, I used a day as really just a buffer, to make sure my heart was in the right place, and it wasn't just an overexcited reaction to go for it. But, you know, fear wasn't really a word that was part of the equation, for whatever reason it be. Part of the reason for it, too, was that Mercedes was involved kind of invocational work for special needs, for about nine years prior to this. So, I was used to seeing her with people with special needs all the time. And so, for me, seeing that she already had this incredible comfort and level of care for people with special needs anyways, it actually it didn't seem like an unnatural idea. And, like she said, we just, however many months, maybe six months prior, had just come off that trip of Haiti. And being around some really severe situations, just being around a lot of kids with a lot of needs. That really became this moment of, "Oh yeah, we could do this." And how we had got to this point, we've had a few friends with Down syndrome. And so, we love those kids, and we love those people. And it really didn't seem that hard, actually, I wasn't scared at all.

Gerald: Well, what was the reaction of your family when you said, "Hey, I think we are going to do this." What were some of their thoughts?

Mercedes: They were actually super supportive, and not really too shocked. Like my mom. I remembered telling my mom, and she's like, "Okay." Snd she wasn't shocked at all, because I'm kind of a go-getter, and she's always known that I wanted to adopt. And she's always seen me in my different roles that I played in the special needs' community, so she wasn't surprised at all. Andy's family, they were super supportive as well, wouldn't you say, hon?

Andy: Yeah, we told them around dinner around Christmas. They were excited because it was our way of telling them we are going to pursue having our first child. And I think they instantly realized that it would be, you know, a beautiful thing to accomplish. All the while, I do think they did express, like, kind of the normal concerns. Like, "Okay, are you sure about that?" Like, "Are you guys thinking about what that might be like?" And I know that some of those questions are, like, on the table, but they were always supportive of the idea.

Gerald: You've had Sunflower now since she was three days old, and she's four. What have been some of your greatest challenges raising her thus far?

Mercedes: Baby years were breezy. She was the best baby ever. I think now that she's four, it's kind of like the hard question, because I'm so in it now. I'm trying to pinpoint if it's just her being four, or her being a girl. Just like a lot of sass, and a lot of bossiness. And I feel like it's no challenge because she has Down syndrome. It's mostly a challenge because she's my oldest, and she's my first go at everything. I think the hardest part for me, since we have two other ones as well. We have Rhodes and Shepherd, who just turned 5 months, getting the complete attention and extra care that I feel like Sunflower needs and deserves. In the little moments, just how I handle maybe a little disagreement between her brother and her. Do I turn into a different direction, or do I say, "No that's not fair, give that back to your brother?" Or do I say, "Rhode's, you know, let Sunflower play with that, she's really interested?" I'm just constantly having this tension of what do I give in to, you know? Is this moment that she's having, is it because she has Down syndrome? Or because she's four, does that make sense?

Gerald: Certainly, it does.

Mercedes: I'm always juggling on that I actually have a lot of expectations for Sunflower. Not expectations in a negative way, but I see her just so much. And I never want to play it down for her, and because of that, too, I always doubt myself. "Oh, am I pushing her too hard? Or am I not doing certain type of therapy for her?" Like, there's ABA, but I decided not to do ABA for her. I'm like, "Oh was that a good idea, or a bad idea? Is this a thing she would learn from? Or is speech?" We are really driving into speech right now, and so we are putting physical and occupational therapy to the side, a little bit. But we are doing dance classes, and we are going to the park a lot. So, I just think, with Sunflower, the hardest part is my own parental doubt that I have. That I'm not doing enough, or am I doing too much. Am I letting her just be four years old, or am I blaming maybe a little melt down or attitude she has on maybe her having Down syndrome? And I feel like that's going to be my questions I answer in every single stage. That that just seems so prevalent right now because as a baby, and as a two-year-old she was just so easy breezy. And now as her personality shines, there's just a little more complexity.

Gerald: I'll let Andy speak first with this one, and then you can fill in, Mercedes. What have been your joys in having Sunflower in your life, Andy?

Andy: She's got this turn key reaction to moving in and out of conflict and happiness, you know. There will be a moment where she could be real sad about something, like if she fell or got hurt or whatever, and you communicate the right thing to her to make her feel better. You know, she can instantly snap into this moment of joy, and happiness. That is that, and she's up and going again, as if it was, you know, no big deal, you know. And I see this with Rhodes in some cases too, but her tension doesn't linger. She tends to kind of front face happiness and joyfulness, and wanting to play and finding a great amount of life in a number of things. I mean, she's loved books at a young age, love drawing, painting at a young age. And so, it's been so much fun to, like, see her interested in words on a page, and pictures on a page. And she kind of speaks the story to herself, and she flips pages. And, honestly, watching her be so self-entertained has become a really joyful thing for me. It's neat because some of the information we got regarding our parents, was how her mom loved pets and the outdoors, and she was creative. I always think it's kind of fun to see how those attributes actually come through her, and it's really been a way to kind of identify how much of her personality is really hers. That's just a wonderful. And so beautiful, and I think, too, that Mercedes, she just kind of mentioned this before. In a way to express what's been really joyful, I often get to describe what's been really difficult for me, is that she's actually been very physically able, and really strong since she was young. Even with her low muscle tone, she climbs up ladders, she climbs up hills, she runs down hills. I mean, she's very physically able, but her speech is one thing that's been kind of slow to develop. So, it's been difficult to communicate with her. And at the same time, she's moving kind of quick. To me, that's honestly been the hardest part. But what's so wonderful, is when she gets new words, and when she communicates something different. She figures out a new way to communicate with us. For me, those are probably some struggle moments.

Gerald: That's great. Mercedes, what are some of your joys that you may want to add?

Mercedes: Sunflower, she has the best smile and the best overall cheerful spirit. She's seriously like a sunshine, sunflower girl. She can brighten up a room just with her joy. She's fearless, so we go to carnivals whenever we can, and she wants to go on the biggest ride that she can. She's not tall enough to go on most of the big rides, but she would go on it if they let her. Those are the one's she's taken me to, and I really don't want anything really to do with those kinds of rides, but she is going to bring it out of me. I just know it, you know, and I want to be strong for her. Like, if she wants to do something, I want to be there to back her up. So, my greatest joy is how much she helps me to be fearless, because she is fearless, and I want to be fearless so I can enjoy different fun experiences with her. So, I know she's going to have me going on rollercoasters, and I really am scared of heights and that, but if she's down, I gotta do it.

Gerald: That's great. So, I just had a question that I'm wondering. You mentioned some of the joys, and some of the hard things, and after four years would you have done this again?

Mercedes: Oh yeah, definitely.

Andy: Oh yeah, I don't think there is any question about it.

Gerald: That's great.

Mercedes: It's, sometimes, I forget that she's even adopted. Even though we look completely opposite, because that's just, she's just my daughter, you know. It just feels so real. It's just how she became part of our family. It's just how she became to be. Through adoption it is no different if I would have birthed her, you know, I birthed her from my heart.

Gerald: Sure.

Mercedes: As a lot of adopters would say.

Andy: We are really fortunate, too, that she did not have major medical complications when she was younger. In some of our experience with her in these four years, in some ways in certain moments, we almost forget that she has Down syndrome. Like Mercedes was saying earlier, we have to remind ourselves, "Oh, wait a minute, is this because of her Down syndrome, or because of her age?" Well, because she's a girl, at four years old, which does become tricky, because it's hard to measure how that's all kind of playing out. I think that's what's been amazing, is she is a full person that has Down syndrome, you know, her Down syndrome isn't what identifies her. It's been, I think, just realizing it would be so unfortunate for so many kids to go without great families in the future, just because they were born with Down syndrome. And that became our identity, we afforded had we had the chance to come around. We have been blessed and privileged, you know, to take on any child that needs a family.

Gerald: What advice would you give someone that might be considering adopting? Generally and specifically, maybe to encourage them to adopt a child with a disability, or specifically Down syndrome?

Mercedes: Well, I'd say do it if you are thinking about it. If you have the thought in your heart, and in your mind ,and you're like, "Hmm, I think we could do that." Dive in and do it, it's a beautiful journey. It's scary, but it's scary when you have a child. Adding that person to your life, in general, birthing them or adopting them is scary. You know, people ask me, you know, "Do you worry about Sunflower?" And I always say that I actually worry more about my boys than I do Sunflower. So Sunflower, to an extent, I'll be able to guide her for a lot longer, you know. She's her own person, I hope she has as much independence as she can, but I know she'll grow and we'll just be able to guide her. And our boys, they really go out into the world, and they make their own choices, and I pray that we do our best for them. To realize that they want to get a job, that they want to be great human beings. And, like, for Sunflower it's kind of already assumed she'll be a great human. She's so funny, and kind, and I know she'll have sass. But, you know, she's just going to be so wonderful. Adoption, whether a child with special needs or not, is beautiful and its scary. But children in general are beautiful and scary. It's part of the adventure, and its part of that journey. And I would just encourage someone to just dive in to that if you are wanting to be a parent, and to love on a child. Focus on that, and chase that, and you're not going to regret it.

Gerald: Awesome Andy?

Andy: Yeah, something that Mercedes says about kids. And normal kids, and kids with special needs. And that's usually my suggestion, because that's usually the biggest question, "Well, aren't you worried about this? Aren't you worried about that?" And with any person, there is no guarantee, you know, of how life is going to turn out. I mean, there is plenty of perfectly able people who end up either at the wrong place or the wrong time, or end up making choices that they can regret for the rest of their lives. And to be a parent of children where that's going on, that's devastating all on its own, you know. And I don't think that you could go into any parental situation and expect that you are going to have some aspect of control to a point of satisfaction. This is not how humans work, and so, yeah, in some ways things are a little bit more predictable, in regards to a child and a person with Down syndrome. I mean, you can expect that you are going to have them for a while longer. I think it's going to make life a bit more patient, and that's the thing, Sunflower holds us down in good ways. You know, realizing that we have to speak slower, we have to stop and understand what she is saying. Like, we can't just keep going with the motion. It causes us to pause, and it's kind of one of those bigger thoughts. But, you know, absolutely, like, do I think that we learn so much more from people with special needs. And often we have a lot of offer them. Absolutely any small amount of time you spend around a community that has a healthy pulse regarding special needs, whether it has a bunch of parents with kids, or a bunch of other kids as adults or teens with special needs, you quickly realize, like, you have so much more to learn. Like, when you thought you were going to them to help them, they end up being the ones to help you. So like Mercedes said, yeah, it's not easy, but hey, raising a child is not easy. Easy isn't the end game, falling in love and building a relationship with a child, I mean, that's what you're doing, regardless. And there are plenty of children out there that aren't loved, that need to be adopted. You know, that's the thing.

Gerald: Final thoughts, Mercedes, anything that you'd like to share?

Mercedes: Goodness, that it is my joy, and complete pleasure to be Sunflower's mom. She is the light of our life, and the joy of our home. Her brother and her both are best friends, and Shepherd will soon join them in that. And she is the best big sister. So gentle and kind and sweet to her baby brother. And people with Down syndrome have a lot to offer this world, and they are spectacular and strong and resilient, and they are to be seen as capable loving worthwhile people. And I can't say enough good things to bring awareness that they have value. People with Down syndrome have value, and they are intelligent, and they have so much to offer. They are the best.

Gerald: Andy, final thoughts?

Andy: Sunny is going to be the one that always surprises us in great ways because, I think, we are always kind of waiting for what's next for her, the next big thing. Thinking back when she started walking, what we were told about Down syndrome, or any special need, is like, "Well, okay, getting to this milestone is going to be really hard." You know, like, everything is, like, okay. You know, don't get too worked up. It's going to take a long time to get to speech, it's going to take a long time to get to walk, it's going to take a long time to get to crawling, to sitting, to eating. So you're told, it's just like now, whether those do take a long time or not, when those moments do happen, it feels like victory. It feels like triumph, and you feel it for them. You don't feel like you've accomplished something, you feel like they've accomplished something. And so, I feel like in life, with her, it's going to be these constant moments of these surprises. Not because of what we don't expect her to do, but because she'll do it. And it's just going to be, I think, in these moments when we kind of least expect. It's always kind of behind the wheel of anticipation, so to speak. I guess, like you would say, like, of course maybe Sunny will be independent one day. Where she will be able to live in her own apartment, and that kind of thing, but the day that she's going to come home and say, like, "Okay, I want to do this." That's going to catch us off guard. So, it's kind of looking forward to when that's going to happen. And I think all those moments are going to be so beautiful, you know. Looking back after however many years, and, you know, she's a teen and adult. And what it's going to be like in, you know, all that to be said, there is so much to look forward to with the life that she is going to have, that it's worth raising her in. And I think people miss out a lot on the opportunity to potentially adopt, not just special needs, just even to adopt in general. Because, I mean, unfortunately, I meet so many friends who spend a lot of money on infertility, and all this. And I understand the desire of that, to want to have blood of your own, and your own child. But, you know, for Sunny honestly, it's just no different. What breaks my heart is thinking about how many kids are out there that just they need a home, and they need a family. And tomorrow there's going to be that many more kids added to the system. They are going to be in the same situation, and it's just, you know, we are the kind of parents who are thinking about that kind of stuff. Who are just trying to put our imprint on the world, and love in the best ways possible. We are always ready to talk about it, to share about it. And, for us, it's been a wild journey. It will continue to be. We've been absolutely blessed and privileged to raise Sunflower.

Gerald: Great, you guys are awesome. I really appreciate you taking the time to speak with me about your daughter, Sunflower, and your family. And I really appreciate you sharing your experiences, thank you Mercedes, and thank you Andy.

Thanks for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a nonprofit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website, orangesocks.org for more stories, and to find national and local resources to help parents of children with disabilities.