An Orange Socks story - Sasha and Gary: Down Syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was grateful to Sasha and Gary to meet with me for an Orange Socks interview about their daughter, Zoey. Zoey was diagnosed with Down syndrome in utero and Sasha and Gary were given the opportunity to abort Zoey, but they felt everyone has issues so they wanted to welcome her into their home. Zoey has had such a positive influence on the family, and becoming strong advocates, Sasha and Gary are in the process of adopting a girl with Down syndrome from China.

Gerald: Sasha, tell me, when did you find out that Zoey had issues?

Sasha: Well it kind of started when we went in for the ultrasound to find out if she was a boy or a girl, and they saw she had enlarged brain ventricles so then they sent me like a week later to have another ultrasound, and then they said, “Oh, well we think we see holes in her heart as well as the enlarged brain ventricles.” And I also was kind of switching doctors at the time, but they said the two things combined could really indicate a chromosome abnormality. And so they said, “Maybe you should have an amniocentesis,” and that was the day that they said, “You only have a few days.” So like kind of implying, like, if you’re going to find something out and you want to terminate you don’t have much time. And so, I was like, “No, I’m not going to do it today, then,” because no matter what that’s not going to happen. And went home and, like, talked about it and stuff because I didn’t know if it was worth the risks. And then my husband said, “Well, you know what, it would be really better if we knew because then we could prepare at least.” And so, it kind of went from that. So, at my next appointment they said, “Yeah, there’s definitely holes in the heart, did you want to do the amnio?” And we did, and then we waited, and then my doctor called me and told me. So that was in October of 2009.

Gerald: He told you had Trisomy 21?

Sasha: Yep.

Gerald: What were your thoughts Gary?

Gary: Well, at first I didn’t know what to expect. So, between all our different children, well there’s been different issues. So, with our first one, Monica, she had, when she was born, she had a hole in her heart. Pretty normal, so we are like, “Okay, it might be the same with her, no big deal, we’ll just see what it says.” And then our oldest son, when he was born, when they were doing the hearing test they’re like, “Oh, he can’t hear. He might have hearing loss. He might be deaf.” Turns out the test was wrong. So, we’re like, nothing is one hundred percent, so let’s just find out and we we’ll go from there. You know, we’ve always been like, “Alright, well, let’s just see. Let’s see where this will take us.” It was scary at first. And we’re like, “Okay, well, this is kind of new.” But through all the things we’ve been through, we’re, like, okay as long as we’re together. As long as we keep looking forward on this then we can make it through it. But as long as we know, if we are in the dark then you have to “what if?” and then the “what if” is the worst.

Gerald: Sure. Did anybody have Down syndrome on either side of your family, or did you know anybody with one?

Sasha: No.

Gary: No.

Gerald: So, brand knew.

Gary: Not before that.

Gerald: Okay so how many children do you have?

Sasha: We have 4.

Gerald: 4 children and Zoey is the youngest, right?

Sasha: Mhm.

Gerald: So, tell me Sasha, what’s been the hardest part for you in having a daughter with Down syndrome?

Sasha: I was actually thinking about this earlier today because tomorrow is seven years since Zoey had her open-heart surgery.

Gerald: So, she had heart issues?

Sasha: She did.

Gerald: Uh huh.

Sasha: And for me, that was the hardest thing because that is a big health thing, and we always knew from the time that we knew what the heart issue was, that she was going to have to have the surgery. So, kind of like the waiting for that. Have to keep a really good eye on her, watch for all of these symptoms to make sure the heart issue isn’t making her worse, you know, like more sick than she already was. I think those early days were the hardest, you know, like watching her, she was just really weak. Like waiting like, “Okay, when can we have the surgery?” But then at the same time I don’t really want to see my baby have surgery. Then walking in the day she had her surgery, I kind of lost it, you know, like to see her. And so, yeah, I was thinking about that today, that’s been really the hardest part, the heart stuff.

Gerald: What’s been the hardest part for you Gary?

Gary: The hardest part is I try to be the strong one, but she actually is the strong one. So, the hardest part is getting through that worrying like, “Okay, what hurdles do we have? What are we going to do? How are we going to do this?” And then getting the game plan together, but when it’s all jumbled up to start with, I think that was the hardest part to start with. And the heart surgery was, there was a lot of sleepless nights like, “Oh, is she getting enough air? Is she getting enough food?” There was a feeding issue on top of that, so I mean we’re eyes open. We became experts in just about everything. Okay, if this we need to do this…for she had a G-tube for a while so we had to feed her that way so she can gain enough weight to get the surgery. So, that was another side effect of that, by having heart issue, she was failing to thrive. So, with that she had trouble with eating in order to get her weight up. So, there was quite a delay. She was what about 4 months old before she really came home, came home.

Sasha: Yeah, well she was basically three months when she had the surgery and it was kind of like a 180 after the surgery.

Gerald: So, she improved.

Sasha: Oh, yeah, like…

Gary: Night and day.

Sasha: Yeah, she had energy and like that’s when I kind of always say we started to see her spunk. Like before that, she was kind of weak, you know, she was kind of happy, but just kind of there. But after the surgery, she was stronger and she would actually, like, would fuss. She was spunky.

Gerald: That’s great. Gary, what have been the joys for you?

Gary: The joy is every day she is like a little puzzle, so every day something knew will be shown you’re not expecting it. And it may not come as soon as you thought, but when it does, it sure is a surprise and a gift. So sometimes she’ll come out of the blue, all left field, like, “How do you even know that?” Or her little sassiness and everything else, but that’s just her uniqueness, it’s no different, she’s just her. And then when you see her personality, that’s like the joy of it, and being able to share her with people and let people know not to be afraid, you know. It’s not a bad thing, and they are no different than a person’s skin color, no different than anything else, it’s a person.

Gerald: Yeah, sure.

Gary: Treat them like a person.

Gerald: How about for you, Sasha, what’s been your joys?

Sasha: I mean, everything. I always wanted to be a mom, so being a mom comes with a lot of joy. A lot of challenge with a lot of joy. And it's been, definitely, been the same with Zoey. There's been a lot of challenge and a lot of joy. And I think it's a little bit extra joy because you do see them, you know, some of the things that our other kids did fairly, what you would say, easily like walking and stuff like that, it took Zoey a little bit longer. So, when it's like, "Oh my gosh, she walked." It's extra exciting because you waited a little bit longer for it. Like writing her name, and all the little things like that. It's just a little bit more joyful to see. Especially because sometimes, you know, some people say, "Oh, she may never." People tell me she may never be able to run. She may never be able to jump. So to see her run across a field or she loves to jump, she's been jumping for years, and it still gives me so much joy to see her jump because I still remember someone saying, "Oh, she may never be able to jump." And I see her, and I'm like, she's jumping. So, anything like that is just joyful watching life the way she sees it, that brings a lot of joy.

Gerald: So, tell me what impact has she had on your other children? Your extended family, maybe neighbor's, friends, what impact has she made?

Sasha: People tell me all the time that she has a lot of impact. I think that sometimes from my point of view I don't see it that much as it may be. I know that she has shown plenty of people though that Down syndrome is not what they thought it was because I have had people tell me, "Well, I didn't realize that they could do whatever." It might be and because they've seen Zoey, and she's still young so people are like, "Oh, wow, she can do that." And I'm like, "Yeah, she can do that." I would say with our kids, I don't know if there's like a big, huge difference. She's just kind of their sister, I mean they know she has Down syndrome, but I don't think they see her really different either. So, it's just kind of like, that's our sister.

Gerald: What are your thoughts Gary?

Gary: Yeah, the same thing. A lot of people have preconceived notions like Sasha was alluding to. Like, in their mind, "Oh, I didn't know. I didn't think they could do that." And I'm like, it's not them, it's Zoey. It's a person, it has a name, you know. It's just getting over some of those hurdles or different lenses sometimes we'll have our parenting lenses on, and we'll be like no you aren't getting it. But outside observers it opens their eyes a little bit and co-workers and everything else be like oh really and I'll be like this and this and explain that there's nothing wrong or hey there's this different thing and yeah we do this and that and they're like, "Oh, gymnastics or swim lessons?" And blows their mind how limited scope and view that they had. Like our family, they just gush over her because she'll be the first one to run up to them, the first one to give them a hug. And she'll tell you how it is right or wrong she'll tell you how she feels, so.

Gerald: So, you are going to be adopting a child with Down syndrome do you want to tell me about that, Sasha? When is this happening, and from where are you adopting?

Sasha: We're in the process of adopting a little girl, she lives in China now.

Gerald: Okay.

Sasha: I guess it kind of started years ago after having Zoey. I actually had a friend who brought it to my attention that there are kids with Down syndrome, specifically, in other countries in orphanages that need families. I had never thought about it before. I'm going to cry.

Gerald: It's okay.

Sasha: Sorry. For me, the thought of a parent having to make such a hard decision to not take their child home, it breaks my heart. I can't imagine having Zoey and living in a country that wouldn't support me. Living in a place that said, "You can't keep your baby because they are not worth it." I can't imagine that, and I can't imagine how that feels to walk away from your child. And I do believe that that is the situation for many of these parents. It's not that they don't love the child, it's just it's where they are, there's no support. There's nothing for the parent, and there's nothing for the child. And I think that the parents feel it's their only option, the best life for their child is to see if someone else can give the child a life. And so, for me the realization that there are children with all kinds of special needs all over the world, that are just waiting for families, that really broke my heart. And I had always had a heart for adoption, but as soon as I knew that there could be another child with Down syndrome just like Zoey has Down syndrome, and we know from having her that these kids are still worth a good life. They are worth having a family, they deserve that. And we talked about it a lot over the years, and it was just kind of like maybe someday in the future we can adopt. And I guess that day just came a little bit sooner than we may have planned. I definitely believe that there is a higher power that brings things to us at the right time, and I just was looking at recess rainbow one day and saw this little girl and I just knew I was her mom. And it sounds kind of crazy, but there was this connection and I couldn't describe it in any other way than I just knew that I was her mom. And so, that was in November, and we had to have a lot of discussions and figure some things out, and figure out that we couldn't figure some things out. And it was really a leap of faith because that was the only, you know, it's a step forward, but we did and, yeah, we are in the process.

Gerald: When will it be finalized, do you know?

Sasha: We are close to sending the Dossier to China, which is kind of like all the information and then you just kind of wait to get official approval that, yes, you can adopt this child. It's probably still a few months away from going and getting her, like August at the soonest, probably, so.

Gerald: So just a little less than a year.

Sasha: Yeah.

Gerald: From when you started anticipating, so it takes a while.

Sasha: It does.

Gerald: So, Gary, if I came to you just having found out I that I was going to have a child with Down syndrome, and maybe it's at the 20 week mark, what advice would you give me?

Gary: Well, I guess I would first say, "Congratulations." Then that'd be like, okay, then I would ask how they feel about that. Like, "What are your feelings? What are you concerns?" I mean any child is, you know, "Oh, the money, how am I going to afford this? How am I going to do this?" But if they had any concerns, I'd be like, "Hey, I'm here. We've gone through this so we can empathize with these feelings," and be, "Hey, there's resources, we know of this, we had to figure it out the hard way, but over time you'll find there is a broad group of people in that there are many in you're not alone. And that's the biggest thing. Anything you need, we'll help you either way, whatever your decision is, but just come to me whatever your concerns are. I'm willing to listen, willing to help to do whatever I can to get you the information you need so you can make your informed decision." I guess would be the easiest way to say that. Like, I can't make up your mind for you, so I can just help you in any way that I can.

Gerald: Super. Sasha, anything you want to add to that?

Sasha: I would probably want to encourage someone with a recent diagnosis that even though you might feel scared, it really isn't, it isn't scary to have a child with Down syndrome. There may be things like I said the heart condition, that scared me. So, there will be things that will feel scary, but I don't know if I like using that word, let me think of a better way to say that.

Gary: It may make you feel uneasy, or have some doubt creep in.

Sasha: Here's how I always say it, there's a real fear of the unknown. So, when you hear you're going to have a baby with Down syndrome, most people have never known anyone with Down syndrome. So, it's an unknown, and that is what feels so scary. You don't know what it means, you don't know what that's going to mean for your child or your family, and all the different aspects. But I would say when you have the fear, don't let that fear take over because there is challenges, but the blessings and the joy far outweigh the things that present themselves as extra challenges or challenges that you don't think you might have with a child without Down syndrome. All kids have challenges. We have four, we know that they all, I always say all my kids have special needs. They don't all have a diagnoses, they don't all have Down syndrome, but we're all unique and we all have needs that are individual to us. So, it's kind of a good way to think of it, too, because it's not just about Down syndrome, it's an individual. And every person with Down syndrome is going to have different needs. If you started to compare them, some have medical issues and some don't. They don't fit in a box.

Gary: Yeah, there's no mold.

Sasha: Yeah, there’s no mold.

Gary: Pretty forward.

Gerald: Very good, thank you. Good advice, thank you both for taking the time for driving so far to meet with me, you guys are awesome.

Sasha: Thank you.