

## 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 for meeting with me for an Orange Socks interview about their daughter Zoey who was diagnosed with Down syndrome in utero. 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 that while becoming strong advocates, Sasha and Gary are in the process of adopting a girl from China with Down syndrome.

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

Sasha: It kind of started when we went in for the ultrasound to find out if she was a boy or a girl. They saw that she had enlarged brain ventricles, so they sent me a week later to have another ultrasound. Then they said, oh well, we think we see holes in her heart as well as the enlarged brain ventricles. I also was switching doctors at the time, but they said the two things combined could really indicate a chromosome abnormality. They said maybe I should have an amniocentesis, and that was the day that they said I only had a few days, kind of implying that if you're going to find something out and you want to terminate, you don't have much time. I was like, no, I'm not going to do it today then, because no matter what, that's not going to happen. I went home and talked about it, because I didn't know if it was worth the risks, and my husband said, "Well, you know what, it would be really better if we knew, because then we could prepare at least." So at my next appointment, they said there are definitely holes in the heart, and did I want to do the amnio. 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 she had Trisomy 21?

Sasha: Yep.

Gerald: What were your thoughts, Gary?

Gary: At first I didn't know what to expect, and between all our different children there have been different issues. When Monica, our first one, was born, she had a hole in her heart that was pretty normal, so we thought it might be the same with Zoey, no big deal. We'll just see what it says. Then when our oldest was born and they were doing the hearing test, they said he can't hear, he might have hearing loss, he might be deaf. Turned out the test was wrong, nothing is 100%, so let's just find out and go from there. We've always been like let's just see, let's see where this will take us. It was scary at first, and we thought, well, this is kind of new, but through all the things we've been through, we're okay as long as we're together. As long as we

keep looking forward on this, then we can make it through, but as long as we think we are in the dark, then we have to “what if “and that is the worst.

Gerald: 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 new.

Gary: Not before that.

Gerald: Okay, so how many children do you have?

Sasha: We have four.

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

Sasha: Yes.

Gerald: 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 it will be seven years since Zoey had her open-heart surgery.

Gerald: She had heart issues?

Sasha: She did.

Gerald: Uh huh.

Sasha: For me, that was the hardest thing, because that is a big health thing. 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 while waiting for that, we had to keep a really good eye on her and watch for all of these symptoms to make sure the heart issue wasn’t making her worse or more sick than she already was. I think those early days were the hardest, watching her. She was just really weak. Okay, when can we have the surgery, but then at the same time, I don’t really want to see my baby have surgery. Walking in the day she had her surgery, I kind of lost it, to see her, and so 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 that I try to be the strong one, but she actually is the strong one, so the hardest part is getting through that worrying, seeing what hurdles we have, what are we going to do, how are we going to do this, and then getting the game plan together. When it's all jumbled up to start with, I think that was the hardest part. The heart surgery gave us a lot of sleepless nights wondering if she was getting enough air or getting enough food. There was a feeding issue on top of that, so we became experts in just about everything. She had a G-tube for a while, so we had to feed her that way so she could gain enough weight to get the surgery. That was another side effect having the heart issue, she was failing to thrive. She had trouble with eating so in order to get her weight up, there was quite a delay in her coming home; she was about four months old before she really came home.

Sasha: She was basically three months old when she had the surgery, and it was k like a 180 after the surgery.

Gerald: So she improved.

Sasha: Oh, yeah.

Gary: Night and day.

Sasha: She had energy, and that's when I always say we started to see her spunk. Before that, she was kind of weak, happy but just kind of there, but after the surgery, she was stronger and she would actually 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; every day something new will be seen that you're not expecting. It may not come as soon as you thought, but when it does, it sure is a surprise and a gift. Sometimes she'll come out of the blue, out of left field, and I wonder, how do you even know that? She has her little sassiness and everything else, but that's just her uniqueness. She's just her, and then when you see her personality, that's like the joy, especially being able to share her with people and letting people know not to be afraid. It's not a bad thing, and they are no different than a person's skin color or anything else; it's a person.

Gerald: Yeah, sure.

Gary: Treat them like a person.

Gerald: How about for you, Sasha? What have been your joys?

Sasha: Everything. I always wanted to be a mom, so being a mom comes with a lot of joy and a lot of challenges, and it has definitely been the same with Zoey. There have been a lot of challenges and a lot of joy, and I think it's a little bit of extra joy because you do see some of the things that our other kids did fairly easily, like walking, that

it took Zoey a little bit longer, so when oh, my gosh, she walked, it's extra exciting because you waited a little bit longer for it. Writing her name and all the little things like that are just a little bit more joyful to see, especially because sometimes some people say that she may never be able to run or she may never be able to jump, so it is exciting to see her run across a field or jump (she's been jumping for years and loves it). It still gives me so much joy to see her jump, because I remember someone saying that she may never be able to jump, and I see her jumping, so anything like that is just joyful. Watching life the way she sees it brings a lot of joy.

Gerald: Tell me what impact has she had on your other children, your extended family, maybe neighbors and friends?

Sasha: People tell me all the time that she has a lot of impact. From my point of view, I don't see it as much as it may be. I know that she has shown plenty of people that Down Syndrome is not what they thought it was, because I have had people tell me they didn't realize that these children could do whatever it might be, and because they've seen young Zoey, people say, "Oh, wow, she can do that," and I say, "Yeah, she can do that." With our kids, I don't know if there's a big huge difference; she's just their sister. I mean, they know she has Down syndrome, but I don't think they see her really different. so it's just "That's our sister."

Gerald: What are your thoughts, Gary?

Gary: The same thing. A lot of people have preconceived notions like Sasha was alluding to. In their minds, they think "I didn't think they could do that," and I'm say, "It's not 'they,' it's Zoey. It's a person. It has a name." It's hard just getting over some of those hurdles or different lenses sometimes. We'll have our parenting lenses on, and we'll be think, "No, you aren't getting it." For outside observers, it opens their eyes a little bit. Co-workers and others say, "Oh, really," and I'll explain that there's nothing wrong, or hey, there's this different thing, and yeah, we do this and that. They hear about gymnastics or swim lessons, and that blows their mind as to how limited a scope and view they had. Like our family, they just gush over her because she'll be the first one to run up to them and the first one to give them a hug. She'll tell you how it is, right or wrong; she'll tell you how she feels.

Gerald: 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 who lives in China now.

Gerald: Okay.

Sasha: It started years ago after having Zoey. I actually had a friend who brought to my attention that there are kids with Down syndrome in other countries in orphanages who 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 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. I do believe that is the situation for many of these parents; it's not that they don't love the child, it's where they are, where there's no support, nothing for the parent and nothing for the child. I think the parents feel it's their only option, and the best life for their child is to see if someone else can give the child a life. For me, the realization that there are children with all kinds of special needs all over the world who are just waiting for families really broke my heart. I have always had a heart for adoption, and then I knew that there could be another child with Down syndrome just like Zoey., We know from having her that these kids are still worth a good life and worth having a family; they deserve that. We talked about it a lot over the years, and thought maybe someday in the future, we can adopt. 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. I just was looking at Recess Rainbow one day and saw this little girl, and I just knew I was her mom. 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. 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 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 all the information, and then you just wait to get official approval saying you can adopt this child. It's probably still a few months away from going and getting her, like August at the soonest probably.

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 that I was going to have a child with Down syndrome at the 20-week mark, what advice would you give me?

Gary: I would first say congratulations, then I would ask how you feel about that. What are your feelings? What are your concerns? With any child, you worry about

the money, how am I going to afford this, how am I going to do this? If you had any concerns, I'd say, "Hey, I'm here. We've gone through this, so we can empathize with these feelings. There are resources we know of that we had to figure out the hard way, but over time, you'll find there is a broad group of people in that situation. There are many so you're not alone." That's the biggest thing. Anything you need, we'll help you either way, whatever your decision is, but just come to me with your concerns, and I'm willing to listen and willing to help to do whatever I can to get you the information you need so you can make your informed decision. I guess that would be the easiest way to say that. I can't make up your mind for you, but I can 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 scary to have a child with Down syndrome. There may be things like 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. I would say when you have the fear, don't let that fear take over, because there are 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, and I always say that all my kids have special needs. They don't all have a diagnosis and they don't all have Down Syndrome, but we're all unique, and we all have needs that are individual to us. It's 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 and driving so far to meet with me. You guys are awesome.

Sasha: Thank you.