

An Orange Socks Story: Miggy- Microgastria Limb Reduction

Interview by: President of Orange Socks, Gerald Nebeker

Gerald: I had the opportunity of having an Orange Socks phone interview with “Miggy” about her daughter, “Lamp.” These are the names she uses on the blog of her website, thislittlemiggy.com, which is wonderful by the way. I was so glad Miggy took the time to meet with me.

Gerald: Thank you so much for taking the time to have this interview. My first question is when did you find out that your daughter had microgastria limb reduction complex?

Miggy: We found out at her 18-week ultrasound. I had been a little bit worried because I had not felt a lot of movement. You’re always a little bit worried until you have the ultrasound. My husband and our oldest daughter and I went in, and I mentioned to the tech that I hadn’t felt much movement, and right away she put us at ease and said, “Oh, yeah, there’s the heartbeat, looks great,” and we were relieved that everything was great. We were excited to find out the gender, I had really hoped that I would have another girl as my oldest was a girl, and I really wanted her to have a sister. The tech was kind of quiet, really focused, and at some point, she said, “Yeah, it looks like a girl,” and I was thinking that was really weird because you are so excited so you try not to let it bother you, but usually they make a bigger deal of it or they say, “Okay, are you ready? It’s a...” She was just saying it off to the side, and then after a couple more minutes, she abruptly stood up and started walking out of the room. I said, “Is that it?” She said, “I’ll be right back.” My husband and I looked at each other, and we knew that it wasn’t good. Then my husband, who had been paying more attention to her than I was during the ultrasound, said, “I feel like I thought that there wasn’t a hand on the baby.” I thought that was the craziest thing I’d ever heard in my life. I said, “What? No, no,” and for a split second, I imagined that we would have this little girl who might be missing a hand. I didn’t even really think that happens or that it existed or that it was possible, but then for some people, it happens, but I just I couldn’t believe that. I said, “No, you just didn’t see it right.” A couple of minutes later, the doctor came in, and we asked, “Is everything okay?” He said, “No, no.” I’ll never forget the next sentence he said, “While her head, heart, spine and lungs look fine, all of her limbs are misshapen, deformed or in some cases, missing bones all together.” That was like a punch to the gut, so unexpected. I remember thinking that I have everything, I’ve never worried in my life, I could have never imagined this. He kept talking and kept saying things, all these words spilling out of his mouth about skeletal dysplasia, and it could be this, and I don’t know about dwarfism, and he was just saying all these things and I couldn’t keep up. It was like his words were water on my head, and I was sputtering and couldn’t catch my breath. Finally, when I did open my mouth, I started to ask questions, and I just burst into tears and buried my head in my hands. Our three-year-old daughter didn’t really understand what was going on, and they ended up taking her out of the room kindly and distracting her with coloring. They just talked to us and that was how we found out.

Gerald: Obviously it was a shock to you and your husband. What type of advice did they provide you with at that time?

Miggy: The main advice was that we are going to get you to a specialist ASAP. The biggest thing was that it was such an unknown. Is this a condition compatible with life? Is it not? Is she going to live? Is this fatal? There was just this huge unknown for what it meant. All four limbs -- that's really rare. The interesting thing is that this was on a Friday afternoon, and we were supposed to leave on a family vacation on Sunday. We were doing a Disney cruise and Walt Disney World for three days each with my husband's family, and we thought we would have to cancel, that we can't go like this. We just found this out, so we have to cancel. We ended up talking to a doctor who said, "We can't get you in until Tuesday or Wednesday next week, so if you can go, I would go. There is nothing we can do now. I don't think anything immediately is going to happen. She's not going to be born right away, there isn't anything immediately to worry about, so just go home and collect yourselves, and we'll get back with you as soon as we can." The first thing we did was that we cried, and we mourned pretty hard for the first 24 hours. We ended up calling some family and friends, but you have to realize that we hadn't been there very long at all. I don't even think it was six months, but we had friends in our church who we called, and we asked them to come. They came and gave us a blessing, and we talked with them, and we just prayed. I will say that we felt a lot of peace right away. Then we went on vacation, and we actually had a really great vacation, which was surprising. I think that if I could say one thing that I've learned about that experience is that you really don't know how you're going to react to a situation until you're in the situation. That's not how I thought I would have reacted, and that's not how I thought I would be able to be so calm about it. After that, we had a lot of appointments. The Children's Hospital is a really big deal here, it's really great. We had level two ultrasounds which were more specific about what each limb looked like. We sat down with a team of specialists, and these were sobering events. Here was one of the most amazing children's hospitals in the country, we kept being told, and to have these five men have decades and decades of experience between them say, "I've never seen anything like this," and "I don't know," and "Here's our best guess," was daunting. They handed us a best-guess diagnosis, and I looked at it for about 1-2 minutes, and I said, "That's not her." I didn't say this because it was bravado or my hopefulness, I didn't want it to be that diagnosis. I think that mothers and fathers sometimes have beyond a gut feeling, we are blessed with this deep sense of knowing, and I just knew that wasn't her, that diagnosis wasn't her. I just kept moving forward, and we didn't have answers, and we continued to see the doctor because it was considered a high-risk pregnancy. He had to see us every week to do fetal monitoring, because automatically when you have a child who has birth defects, they are at a much higher risk for being born prematurely or stillborn, so there wasn't a lot of advice or anything to do.

Gerald: What were your thoughts after she came into this world?

Miggy: I looked at her and I said, "She's perfect." It was an interesting period, being pregnant during that time, and suddenly we became really sensitive to things in the world that are so commonplace that suddenly you know they didn't apply to what people say about little babies and little humans all the time. We knew this doesn't apply to this human, little things like 10

little toes and 10 little fingers. We knew our daughter wasn't going to have 10 little toes and 10 little fingers. There was a TV episode at the time on a show we liked to watch where the couple had a baby, and we remember seeing this little baby arm reach up, and my husband and I kind of looked at each other, knowing that wasn't going to be our daughter. But after she was born, she was perfect, and she was ours. I guess this goes back to you don't know how you're really going to react until you're there. Because in my 20s if somebody had had a crystal ball and said, "You're going to have a child with a disability and she's not really going to have hands," I think I would have thought that I was going to freak out every day of my life, that I'm going to feel so worried, but I didn't. We just loved her, we just knew she was ours and we were so grateful for her. There didn't seem to be issues because that was a huge unknown, as I said, they didn't know what we were dealing with. Over the course of the meeting with doctors, it looked like most likely she would live, they couldn't see any reason why she wouldn't. There were some questions, like they couldn't find her stomach for a long time, and it is very, very small, so they thought there was a little worry if her esophagus was going to be blocked when she was born. We didn't know that there were some questions about that. My husband is doing his residency in pediatric dentistry at the Children's Hospital, and he sees a lot of kids with disabilities. He said, "There is never just one thing, honey. There are probably going to be all of these things." We were kind of prepared for a lot of complex issues, and actually I remember one time one of the many specialists that we saw at that time said, "You know, it's very possible that this could just be a physical issue, that she has no other medical complications and that she's just like any other baby who goes home with you after four days." I was kind of mad at that doctor because I thought that he was kind of setting us up for disappointment, but that's what happened.

Gerald: How old is she now?

Miggy: She is seven now and is at school right now. She is in first grade. Her little sister and I just went to her field trip this morning. She had a couple of other medical issues as a baby, she had a G-tube because the small stomach did end up being a little bit of an issue, and so while she was always fed orally, she was supplemented through a G-tube for about a year. Other than that, it's just her limbs that are affected.

Gerald: What have been some of the hardest things about having a child with this diagnosis?

Miggy: The hardest are the social implications and what it means for her to live in a world where she has very visible differences, so she never flies under the radar when we are out in public. She has a wheelchair, then on top of that, she is missing most of her left arm. Her right arm is also much shorter, it stops where a typical elbow would stop. She doesn't have fully formed hands. She has a hand that has three fingers all fused together. Her legs are shorter and are different lengths. It's not hard being her mom, but it is sometimes hard being her mom in a world that doesn't readily recognize and know what to do with someone who appears so different on the outside.

Gerald: Tell me about the joys.

Miggy: The joys are one of the main ideas I try to share on my blog. I think for a lot of special needs families, ours is a journey from fear to love. We had that terrible ultrasound appointment, it was just blinding fear, fear for the future, fear for us, fear for this girl, and what does this mean. The joy is that you love her as much as you do the rest of your kids. When we got that ultrasound appointment, it felt so definitive to have a doctor saying that all of her limbs are affected. It sounded so grim, everything about it sounded so grim. What I've realized now is that I appreciate that we had an ultrasound appointment, and I appreciate that we had some information up front about her. But it was so inadequate in telling us the picture of who she is. She is such a naturally happy and joyful kid, and she always has been. She always has the best laugh in the whole world. She is funny and bright and says the most hilarious and sometimes inappropriate things that make us laugh. She is a joy to raise on every level, and then on top of it, my eyes have been completely opened as I'm sure yours have because like you, I also interview families who have had kids with disabilities or individuals who themselves have disabilities. My eyes have been completely opened to this whole new world of what it's like to live in a body that is disabled. I see it from this whole new perspective. She is the same, I mean yeah, she does things differently. Sometimes people think we use euphemisms like she is "differently abled," but it really is true. She writes with her feet, and she can feed herself with her feet. Her feet are her hands. For a while in school, she received occupational therapy. She still receives physical therapy, but after a while, they said they couldn't give her occupational therapy anymore because she writes at the same level as her peers and they couldn't justify it. I really do see through her what humans are capable of, and I feel like I see ability and possibility whereas before, I really did just see disability.

Gerald: What has been her impact in your opinion on her siblings, your extended family or friends and neighbors? Have you seen that her life and her abilities have had an impact on them?

Miggy: Absolutely. Again, I think there wasn't anyone in my family or my husband's family who we knew that was born with a disability. My mother-in-law does have MS, so that was something that she's had to learn to adapt to over her life, but I think that's different from someone who is born with a disability. It helps for people to know and see someone they love who is disabled, because I think that naturally in our society, there's a great discomfort with disability. A lot of us grew up at a time when kids were really segregated, mostly from school, so if you're not around disability, you're just not familiar with it and thus you're more uncomfortable. It might feel a little more fearful and foreign to you. In our family, we all know someone with a disability and see how wonderful she is and how loved she is. Yes, she is disabled, and that label doesn't bother me, and I hope it doesn't bother her because that is a part of who she is and is nothing to be ashamed of or afraid of, but at the same time, she is not one thing, and it is not the whole of who she is. At school, I think it has been a big impact on her teacher. He says she is wonderful, and she really does want to be like the rest of the kids. Something that we had to learn and the doctors would tell us is that when it comes to therapy, when it comes to her ability, she is going to show you the way, she is going to lead the way. We never told her to start using her feet to draw, that's what she figured out was best for her. Yeah, I think that she's had a great impact on people, mostly just being around someone who

has a very noticeable physical disability, but seeing that she is pretty much like anyone else, a lot like the other kids. She needs accommodations, but so do most of us.

Gerald: Certainly, and that's great. I'm just wondering, if I came to you just having had a child or in utero discovered I had a child with a similar diagnosis to that of your daughter, what advice would you give me?

Miggy: My first advice would just be that it is okay to mourn and to feel sad. I don't think there is necessarily anything wrong with that. The only reason I say that hesitantly is because I don't want anyone to feel badly if they do mourn. We mourned, and we felt bad. It's just hard for me to say that now because there's nothing sad about my daughter. There is nothing sad about who she is and her disabilities. At the same time, as most of us are so unfamiliar as to our ideas of what disabilities are, it is hard, and so you mourn. I think it is okay to go through that, feel the sorrow and feel the sadness. We have so many resources with the internet today to be able to connect to families and to connect to other organizations, to be informed and look stuff up, to do some research and connect with other moms. I was fortunate enough to be able to talk with other moms before Lamp was born, so I could just talk to them to know what it was like. One thing I will say though, too, is that with limb differences, no two are exactly alike; it's just a huge broad range. I mean people who are missing one arm is a very common limb difference or missing one hand below the elbow. That's vastly different from my daughter, who has involvement of all four limbs, doesn't walk, uses a power chair, and who doesn't have a single hand to grab with an opposable thumb. You really have to try to be very open to realizing that talking to one person is not going to be the same, and you have to really think about your individual child and how each limb is affected and how they all come together. My other advice would just be to remember that ultrasound machines, while helpful, are not future-predicting machines. They can't tell you about your child's wonderful personality or the amazing things they are going to teach you. There is so much that the ultrasound machine couldn't tell us, so just keep that in mind, that it's a small piece in the whole of who this person is. There are just so many resources today, whether it's a power chair or that your kid might need prosthetics, OT and PT if you live in America where we are fortunate to be able to get different resources that are available. There's a lot to be hopeful about, and they are going to figure it out. I do think that it's a lot harder for people who lose limbs than if you're born the way you are. That's the only thing you know, and you function that way. My daughter isn't missing any arms, it's how she was born, and that's how she functions just like the rest of us. We use what we've got to the best of our abilities.

Gerald: That's great advice. I appreciate it, and I appreciate your talking to me to do this Orange Socks interview. You're awesome. I'm just thrilled that I had this opportunity to meet you via the phone.

Miggy: Yeah.

Gerald: And for having you share your wisdom.

Miggy: Yeah, absolutely. Thank you for the work you do. It's always great to meet other people trying to spread positive messages about inclusion disabilities because I really think it takes a village for us all to do it.