

An Orange Socks Story: Natalie - Rett syndrome
Interview by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In this episode I speak with Natalie about her daughter, Sophia, who has a number of disabilities.

Natalie: During the ultrasound I was in shock. I thought, "There is no way I'm strong enough to handle this. I can't do this." I felt trapped and afraid. I had four weeks to prepare for this unknown life. I needed to get through it with the least amount of stress because my baby could feel my stress. So, I decided to hold onto hope that everything was going to be okay and that's what got me through, but I was so scared.

Gerald: Natalie knew in utero that Sophia would have some challenges, but the extent and number of challenges couldn't be known.

Natalie: When she was born, she was born with more issues than they could see on the ultrasound, and I remember asking everyone in the room, "Is she okay? Is she okay?" Because doctors and specialists were working on her in the corner, and no one would answer me. At that point I knew that everything wasn't okay.

Gerald: Natalie describes when she found out her daughter Sophia would be born with disabilities and the moment after Sophia was born, when the shock faded and she realized that her baby needed her.

Natalie: They finally lay her on my chest and she blinked and was staring right into my eyes, and I was still in shock because I hadn't seen another human being who looked like her. I just remember thinking, "This is my baby I need to comfort her." I reached out and then they took her away. I didn't see her until later that night and, honestly, I was scared and I was avoiding it. I was afraid of this new life that I didn't know anything about, and it meant facing it the moment I went to see her in the NICU. There was a point where the nurse was baby talking to her before she handed her to me, and I just broke down crying because in that moment the shock faded and I realized, "This is my baby." I held her and I cried and the nurse held me, and from that moment on I said, "I don't care about anything else other than protecting her and doing whatever it takes to keep her happy and safe and loved."

Gerald: Sophia's issues are complex and she has several diagnoses.

Natalie: Sophia has multiple diagnoses, she has Rett syndrome, it's a neurological disorder that basically takes your ability to walk, talk and do things for yourself. Away from you, kids develop typically, and around 1 years old they regress and they lose all their skills. We thought the only issue Sophia was going to have was the deformities and the challenges that come with that. She was developing typically for everything she went through and those skills began to regress.

We didn't find out until she was five years old that she has Rett syndrome. Before that, she began to get sick all of the time, we found out she has an immune deficiency. It's a rare immune deficiency that only six people in the world have. She began to have seizures, which is caused by the Rett syndrome, and she has Type-1 diabetes. Rett syndrome really is the biggest challenge because it basically traps you inside your body. She has a lot of neurological storms, and to me that means seizures and tremors and her brain won't do what it wants to do. There are times when things calm and she can focus and she is able to move her arms and do things. She does have different ways to communicate with buttons and switches, and also, she really communicates with her eyes. You really don't need that many words to be able to express yourself and communicate. So, you know, she has to deal with a lot of challenges every day, but she does it with a smile. She is just the sweetest, most positive little girl.

Gerald: Natalie describes the unique challenges that Sophia faces.

Natalie: There's a scientist in California that discovered it's a gene that's impacted, and the other people have differences with their mouths and hands, but they are not as severe. The Rett syndrome, it's a gene mutation on the Mec p2 gene and, of course, Sophia's mutation is one that has never been documented before. She's like no one else in this world, and no one else has this combination of conditions and looks like her, although we found a girl in Siberia who is very similar.

Gerald: Despite loving a child with a disability, there is a mourning process that any parent feels along this journey.

Natalie: That four weeks before she was born, I definitely was mourning. I felt it again at certain times after her birth, like when you would see other children around her age doing things that she couldn't do. And when she lost her skills at around one and a half or two years old, that was another moment where you mourn the loss of her voice, or her doing the itty-bitty spider. Just little things that you appreciate so much more now that they are gone that she was able to do them. But there came a point where I accept Sophia for who she is, disabilities, deformities and all. There's no mourning in me because she is her own person. She is amazing, she is true beauty, strength, and I accept all of her. I love her and I accept all of her disabilities and differences. There was a time early on, I mourned the loss of the dream of what I had. I wanted to be a mom since I was seven years old, and so there was a dream there. I had never considered having a disabled child, there was that feeling of loss, but that feeling is gone and it's replaced with full love and acceptance.

Gerald: Family support is an essential part of promoting health, healing and hope

Natalie: Our family was amazing. They embraced and accepted Sophia right away, my husband's parents and my parents and my sister, they would all take turns going to the NICU though Mark and I were there every single day, and Mark would have to peel me away after 10-12 hours. They were there every day visiting her, loving her and it's still like that to this day. My family is absolutely amazing, I have to convince my dad to let me get her to do her feeds or

whatever. He just always wants to be with her and hold her when he's here. My mom supports us, and my sister, she's actually a nurse aid and is becoming a nurse because of Sophia and she helps us. I feel like I couldn't do it without them. My husband is incredibly supportive he is there for everything and for everyone and he really is my rock. He had the same mourning periods that we did, and he has a different way of handling things than I do, but mostly we have been on the same page. For us it brought us closer together, we have been through unimaginable things and challenges and heartache, and yet it brings us closer together. Our families have been amazing.

Gerald: Specific challenges related to public perceptions can be especially difficult.

Natalie: One of the greatest challenges is she does experience some struggles and pain at times and she can't tell me why. So, there are times when she is crying and all I can do is be with her and comfort her after I've gone through the routine of trying to alleviate any type of pain. We have a full routine of that, that was really hard until I realized she just needs me there with her. I will comfort her and work with her through it.

Gerald: Natalie shares her pain from others reactions to her daughter's differences.

Natalie: The biggest challenge for me has been taking her out in public. We knew it would be a challenge, but we did not realize that it would be as bad as it was. I remember taking her to Philadelphia to the children's hospital there. We were just walking the streets of Philadelphia, and she's five months old, and my husband has her in the green carrier, and the moment that broke me was two teenage girls walking by and screaming at the top of their lungs as if they had seen a monster, and then they began to laugh. Before that, I had noticed all the stares, the non-stop whispers, the mean comments, and that was the moment that kind of broke me. I said, "I can't do this." It was a pain that almost brought me to my knees, people were so hateful and so unaccepting of my child because she looked different, and I'm thinking, "This child has been through so much and overcome so much and she's amazing, and yet all they see are her differences." We were discriminated against. We took her to her first pumpkin patch experience and we were excited and there were other kids there. You get the stares and you already start to feel tense, and the ladies checking those kids out were talking, and laughing, giving them stickers, and the moment we walk up she won't even look up at us. She won't acknowledge us; she didn't offer my daughter a sticker. Things like that caused me to retreat. Having to build up so much strength to go to the grocery store, only to be knocked back down again was really difficult for me. I struggled with it, and so I chose to remain pretty private. We would still go out and do things, and when I was feeling strong it was, "Okay, you can do this." That was the hardest thing for me. It tapped into all of my other insecurities that I had, just alone as a person, and the rejection it caused. It was probably one of my greatest pains, having people treat my daughter differently and cruelly.

Gerald: Natalie shares some tips about how to be kind to people with differences.

Natalie: I always appreciated the people that would smile and say hello and approach us in a kind manner. I'm okay with questions here and there, as long as they are genuine questions because you want to learn and educate, not because you're being nosy. A smile and a hello, and acknowledging my daughter that is there is what I would appreciate. First and foremost, just educating your children to begin with about differences, facial differences and disabilities. You can do that in the comfort of your own home. That's where it starts so that it's not a big deal, and so they know what people with disabilities and facial deformities look like, and that they should be accepted and loved just like everyone else.

Gerald: Sometimes caring for a child with a disability sparks people to take action, and wow, Natalie has really become an advocate. She changed Twitter's policy regarding hate speech against people with disabilities.

Natalie: My advocacy started really to fight for health care for disabled children, and to ensure that they are still receiving the healthcare they deserve. While I was fighting, I got so much hate, death threats, just really extreme things happening that put us in the public eye. Someone used Sophia's image to promote abortion and I decided enough was enough. I wanted to have it removed, and Twitter at first found no violation and that really angered me. I have a great following, and so I asked them to help me and we shared it, and I shared the story and it went viral throughout the world and, of course, Twitter took it down. That is when another mother, an amazing activist, Julie, said, "Hey, they don't even have a place to report hate speech for disabled people. You can report hate speech for race, religion, gender, orientation, but not disability." So, if there is not a proper place to report it, then there's often times not going to be a violation. So, I just started a campaign to get Twitter to change that. With the help of so many amazing people and the large community that follows us, we were able to get Twitter to include disability in the reporting tool. The fact that it wasn't included already just speaks volumes. Often times disability isn't included in many talks about diversity and inclusion. All of that kind of shifted my advocacy. The hate that we continue to receive, I try to expose it to change it because there's such a stigma still surrounding disabled children, and children with facial deformities. I think about the 1950's when disabled children were shipped to institutions, if that hadn't happened, we would all be used to it. It wouldn't be a big deal. Disabilities wouldn't be a big deal, facial deformities wouldn't be a big deal. Which is why I allow a glimpse into my home and our lives to normalize those things, and for people to see that even though there are challenges and heartache and a lot of things that are involved with my daughter's condition, there's still so much happiness and love. Amazing things come from my daughter, and she is true beauty and she has value and she is successful in my eyes. I'm so proud of her and I really want to change societies definition of what beauty, success and value are, and that's what I fight to do.

Gerald: Sophia's siblings have developed a strong sense of compassion, empathy and acceptance.

Natalie: I really believe that they are growing up knowing what compassion is and knowing what acceptance is. They know what true beauty is and I learned that later in life. I think that they will

be amazing human beings, and they already are. I don't want to put pressure on them to be these spectacular people, but my five-year-old wants to be a doctor because of Sophia. I'm sure that will change, but that's the way they think and they want to help out with Sophia. They don't care about differences, it's just not a big deal. I think they are going to be more compassionate and accepting. They see the work I do and they want to be involved a lot of times, and they want to help others. Just the other day they were pretending to create their own nonprofits, and it was all about helping people. In that moment, seeing them in that way and come up with their own nonprofits to help other people, I realized the impact my work is having on them is really positive. I'm excited to see how they are as adults.

Gerald: Natalie offers some priceless advice for parents in similar situations.

Natalie: I would let you know that you are stronger than you think you are. Your love for your child will likely be stronger and more fierce than you could ever imagine because there is an extra level of advocacy and protection that you will have to deal with. You may be sad now, accept those emotions and allow yourself to feel them so that they can pass. You will accept and love your child just like any other child. It's the most difficult thing, but it's also the most amazing thing. I have dealt with extreme sadness, but because of that, I feel extreme, real true happiness. She is so important to me and she has changed me for the better. I'm a better human because of her. I really do believe that even though there are so many challenges, life is just so much sweeter because we appreciate the small things and we learn to live in the moment.

Gerald: Finally, Natalie describes the nonprofit she founded.

Natalie: I started an organization called *Sophia's Voice* in Sophia's honor. Sophia has a voice, even though it's not a typical one where she can speak. She has a voice and it's extremely powerful, and because of her voice I am inspired by others. Her voice is loud and powerful and she speaks with her eyes, her heart and her soul. My advocacy within Sophia's voice is to encourage acceptance and inclusion of profoundly disabled children and children with facial deformities, and to help people with disabilities receive medical equipment, help with medical debt, for caregivers to receive respite, and for disability activists receive fun gifts or just helping them with their advocacy. It's all because of Sophia. All the work that I've done, everything that I do, the strength that I've found and the voice that I've found, it's because of her.

Gerald: Please check out Natalie's nonprofit organization *Sophia's Voice* at sophias-voice.com. Check out the CNN account featured there. The heart-wave logo at the top of the page is Sophia's heartbeat, and in solidarity, Natalie has a corresponding tattoo on her arm. I've only met a few people in my life who have changed the world for the better. Natalie is one of them, and I'm so honored she took the time to speak with me.

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

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