

An Orange Socks Story: Angie- Stromme Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was very happy to have an Orange Socks interview with Angie over the phone about her daughter, Ruby, who has Stromme syndrome, a very rare condition.

Gerald: Angie, thank you very much for taking the time to talk with me about your daughter, Ruby. Can you tell me when you found out that Ruby had Stromme syndrome?

Angie: I found out when she was in the NICU that she had a rare genetic condition; however, at the time, it did not have a name and was just a listing of various symptoms. It goes back to when I was pregnant with her, and I found out at my first ultrasound that she was not developing properly. Her head was smaller than it should be, and at that point, I was referred to a perinatologist. The news just kept getting worse and worse. They thought at one point that she had trisomy 18 or 13, so they encouraged me to do an amnio, which I did. I didn't want to, but I did it after being pressured pretty significantly, and that test came back normal. The doctors still said they didn't know if she was going to live to birth. One thing I was offered was abortion, and I said no. I was on the internet about a year ago, after someone told me that the condition had a name and that they knew someone else who had the same condition as Ruby, so I looked it up and sure enough, it had a name. Over the years, that was kind of a cool experience because now I can reach out to other people to see if they have that condition as well.

Gerald: So, was Ruby born without issues, or did she have complications at birth?

Angie: She had a lot of complications at birth. Through the course of my pregnancy, we discovered that she had a bowel obstruction. They told me she would need to have surgery after she was born to fix the bowel obstruction. Part of Stromme syndrome is microcephaly, vision impairment and bowel issues, and hers was a bowel obstruction. When she was born, she wasn't able to eat because she would just throw it up right away. We had her surgery done when she was four days old, but we also discovered that she had a vision impairment like the first day she was born. She was just really slow to develop, and she cried a lot. After her surgery, she had to stay in the hospital for 56 days to grow because she was born at 3 pounds 9 ounces. She needed to gain weight and learn how to eat. There were a lot of ups and downs in the NICU, but she was just getting healthy enough to go home.

Gerald: That's amazing. How old is she now?

Angie: She is 12.

Gerald: Wow, so in these 12 years, what have been the hard things that she and your family and you have gone through?

Angie: There have been a lot of hard things, but having a child in the NICU is one of the hardest experiences that a parent can go through. I'm a single mom, so that was particularly difficult for me. My family is really supportive, but going through that alone was challenging. Then when she came home, it was appointment after appointment, every day having to go to a different doctor. In the beginning especially, it was touch and go what's going on with her, because she had all these things that had never been documented before, or at least we didn't find the information or its syndrome. A lot of kids have had that, so there are charts and graphs, and we were kind of going blind. It was hard finding the right doctors and getting to those appointments on my own. My mom was there for me, and my parents were there for me and my sister, but a lot of it I've had to do on my own. Once we got through the initial medical talk, then it was coming to terms with the diagnosis and trying to find our normal. We know now what is normal for us. We worried when she started school, "Is she going to be bullied? Will she be accepted? Will she thrive in school?" I would say there have been challenges every step of the way, but it has also been amazing.

Gerald: That leads to my next question, what have been the joys over the last 12 years?

Angie: The biggest joys have been the fact that there were so many doctors who said to prepare for the worst, "She's probably not going to walk and she's probably not going to talk." Time after time, Ruby has proven them wrong. The most amazing thing for me has been the way people have come into our lives to help us to achieve these things I used to worry so much about, like would she be able to go to school or day care or just normal things that kids are going to do. It feels like every time I would be so worried, just the right resource and person or clinic would come into our lives and would give us the ability to make it happen. That has been so incredible. The people who have rallied around us with the joy and the inclusion for me have been huge. I worried so much that she would be bullied in school and that she would not have any friends, and I am not worried about her because she is one of the most popular kids at school and is so well-loved. We had a recent experience using social media that has been really amazing, and I can go into detail with that if you want to know more about that.

Gerald: Sure.

Angie: It's pretty cool.

Gerald: Go ahead.

Angie: I've had an Instagram account for a long time, a little over a year, and I've been posting videos and things about Ruby. I met a woman online who runs an account where she features different diagnoses, it reminds me a lot of what you guys are doing with outreach and setting awareness, she encouraged me to start sharing

Ruby's story more broadly, and she featured Ruby's story on her website. Overnight I got a couple hundred new followers, and it was amazing. I started sharing more and more, and last week I decided to share a video of Ruby doing a Q&A with me about some questions that our followers had for her. Some of the questions were, what's your favorite animal? What's your dog Polo like? Who's your favorite person? etc. I recorded this pretty simple Q&A with Ruby and posted it on the Instagram account. The next morning, I had 40,000 views, and I thought, "Oh my gosh, what is going on here?" Over the course of the next three days, it got to over a half a million views and 1,000 comments. I then went from having 7,000 followers to almost having 13,000 today. I'm so excited about all this attention. I wanted it to matter, I wanted it to matter for Ruby. People were asking me what can they do for Ruby, they want to do something for her. I decided to start a GoFundMe for her because I've always wanted to get her a service dog to help her with mobility and independence. I thought that I'd just put this out there and see what happens. I set up the GoFundMe page on Thursday with a goal of \$15,000, and we raised the money by Saturday or Sunday morning, so in three days, we raised over \$15,000 for Ruby to get a service dog. I can't even describe the amazing experience that we went through in doing that. We've been on the news since then being interviewed, and I just feel so blessed at the outpouring of love and acceptance that we've seen.

Gerald: That's a great story, thank you for sharing it.

Angie: Yeah.

Gerald: I'm curious, what impact has Ruby's life had on your immediate family or friends or neighbors?

Angie: I think that Ruby has totally united our family. She has brought so much joy to all of us, and I think that truly going through that really hard experience of her not almost making it was so hard for our family at the time, but it strengthened us and brought us closer together so that now we feel like we can get through anything together as a family. We've already been through such a hard time, and Ruby has grown and developed and gotten her own huge, loveable personality. She has blessed so many other people just by her smile and her laugh. She is just a joy-bringer, that is all I can say. She brings joy wherever she goes, and I just feel so blessed to be her mom.

Gerald: That's great. If I came to you just having found out that my child had Stromme syndrome, or had been diagnosed with Stromme syndrome, what advice would you give me?

Angie: I guess I would say that you've been given an incredible gift and an incredible responsibility. Being so hard right now when you don't know what to expect, you're probably scared out of your mind, but I promise you that if you keep the faith and allow your journey to unfold, you will be blessed with incredible miracles and amazing experiences that will enrich your life in ways that you never thought

imaginable. It's going to be really hard at times, and you're going to think, "Why me?" But I think that those challenges really strengthen you and help you become the person that you were meant to be. You can't focus on the things that don't matter, you can't focus on "Keeping Up with the Jones" and material possessions and all of those things. All that matters is that you have to keep doing what's best for your child. I would just say take it one day at a time and pray and try to focus on that, and watch your child become something amazing, no matter what their ability is. Every kid has something to give the world, and you get to be the person who shows everybody that, and it's an awesome thing.

Gerald: That's great advice, thank you. You made a decision not to abort Ruby when given the chance, when issues were discovered in utero. You have had a journey that's been fraught with various difficulties, as well as blessings, and now she is 12 years old. Has that journey been worth it?

Angie: Oh, yeah, I have been asked if I could change anything, would I do it, and I say every single time that I wouldn't. This is exactly what my life was supposed to be, and I think that Ruby has her own unique role in this world. I understand that some people might wish that they were typical, and why wouldn't I think that, but I know that Ruby has love and joy in her life and that her role is to give it back to everyone. I would never change a single thing about this journey, it was 100 percent worth it.

Gerald: That's super. Any final thoughts?

Angie: I just remember feeling so alone when Ruby was first born, and I think we are so blessed now in a world where social media can be used for good like what you guys are doing. It is amazing, and we are so lucky to be able to come together on a platform like yours with your authority. I used to hide away a little bit, not that I didn't want to show Ruby, but because I was afraid of the people not being accepting of her, but I found my own healing in sharing her story. I encourage other parents to share their stories in a way that feels right to them. There are a lot of personal feelings in that and in connecting with other families.

Gerald: That's super, thank you so much for speaking with me. It has been an honor.