An Orange Socks Story - Katie and Eric: Congenital Nephrotic Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Katie and Eric, I am honored that you would take the time to meet with me to do an Orange Socks interview about your daughter, Emerson, who has congenital nephrotic syndrome end-stage renal disease. Is that correct?

Katie: Yes.

Gerald: When did you find out that she had this issue?

Katie: When she was around eight weeks old. There was a suspected issue when we were pregnant, but it wasn't diagnosed until the eight-week mark. She developed a fever, so we took her to the emergency room, and I remember that within a few minutes, the ER doctor asked me if she normally typically looked like that. I said that she looked like this when she was born. The doctor said she had a feeling that there was something critically wrong with our daughter. They ran a series of tests, but they couldn't determine anything at that point. We were admitted and were in the ICU for about a week. They went from thinking it was her heart, to her gastro system, and then they finally settled in on the kidneys after about five days. It really felt like an episode of "House." Every day was something different, different ideas, a different theory, and a different specialist who was coming in. Once they would rule things out, they finally zeroed in on the kidneys. I remember the nephrologist coming in and telling us that she suspected congenital nephrotic syndrome. It's a rare genetic issue, so she wanted to run a few more tests, but she didn't want me to Google it, and didn't want me to research it because it would scare me.

Eric: She did Google it, though.

Katie: As soon as she left the room, I asked myself, how do you even spell that? I've never heard of that before. Enter good ol' Google with autocorrect, "Oh, did you mean this?" I pulled it up, and it was terrifying. The first thing I read was that most patients don't live past the first year. I mean, it was heart breaking, not knowing what was going to happen, or what her prognosis was going to be. The next day they tried telling us that we were going to have to go to Houston because they didn't have the experience or the specialty to treat her here, and the nephrologist there was amazing. She was very honest and told me that she would be honored to treat her, but she needs a specialist with more experience because she had never had a patient with congenital nephrotic syndrome. As soon as they said Houston, we said, "No, we have no family there." However, if that's where she needed to be, we would have gone. Thankfully, the nephrologist who she sees now is amazing. They called him, and he said, "I've had patients like that with a great outcome, so transfer her over." After a week at our first hospital, we were transferred to the university hospital, and that's been our home away from home ever since.

Gerald: How old is she now?

Katie: She just turned two in August, so today she’s actually 26 months old.

Gerald: Oh, terrific.

Katie: And ironically, today is actually the day two years ago when we were admitted to the hospital originally, not knowing what was wrong, so it has been exactly two years since her journey started.

Gerald: What have been some of the toughest things that you two have faced?

Katie: I feel like not knowing. She has definitely not been textbook at all, by any means. She is writing her own novel here, and every day it’s something different. Also, trying to juggle not only her needs, but our older children as well is a job. They are seven and five, and not only did our world change overnight, but so did theirs. I primarily stay at the hospital with her.

Eric: That’s the hardest part right there, when she gets admitted. She doesn’t stay for 24 hours, it’s usually two to three days, sometimes weeks at a time. I work nights, so I get home from work and watch the girls all day.

Gerald: That would be hard.

Katie: I have my mom come over and spend the night with them, so that way he’s still able to work.

Gerald: Sure.

Katie: I had to quit working in order to care for her. I tried to go back to work, but it’s impossible.

Gerald: Yeah.

Katie: Between all the different appointments and therapies and trying to keep up with everything, it was difficult because she requires 24-hour care.

Gerald: And she is on dialysis?

Katie: She does dialysis every night. We actually do it in our home where we have her machine. She runs for 11 hours continuously, and that essentially is what’s keeping her alive.

Gerald: But at some point, you’re looking to have a kidney transplant.

Katie: At some point. The requirement at our hospital is 10 kilograms, and in order to even be referred to be on the waiting list, she has to meet that requirement. From there, she'll get her referral. We'll meet with the transplant team, and they will do a series of tests, bloodwork, ultrasounds and all different types to make sure that she is not only healthy and can withstand the transplant itself, but that she's also size-appropriate, because she has to be able to fit an adult kidney into her tiny little abdomen. She is 9.8 kilograms and is getting extremely close to getting her referral. We are praying that next month she gets her referral.

Eric: That she gets to be that big.

Gerald: That's awesome. With all the things that you have to do to care for her every day, including having to quit your job in order to do the care with all those hard things though, what are some of the joys that she's brought to your family?

Katie: All of her firsts. It's really made us all more humble. Our older girls know things that most seven- and five-year-olds don't, and you wouldn't expect them to. She is starting to try to walk, and when she takes her first steps, they get so excited. It just really makes us more grateful. She has really brought us all together, more so even our extended family. It's inspiring to see that even though she goes through everything, you wouldn't look at her and think that she's sick. It's hard to be sad and have a pity party when she doesn't, so why should we?

Gerald: If I came to you just having found out that I have a baby or a young child with this same condition, what advice would you give me?

Katie: To not be scared, to understand that even though it's going to be hard, it's never easy, that there are so many different advances in medicine and technology these days. Back then, in her condition, she wouldn't survive, she wouldn't make it to that one-year mark, but now there are so many different treatment options and plans that there will be one for your child. It may be hard now, but it pays off every day. Every night I go to bed, and even if I've had a hard day, even if I know that tomorrow is just going to be the same thing, different day, I know that it's what was meant to be for us.

Gerald: Awesome. Any last closing words of wisdom?

Katie: I think with anyone who is faced with a child with a life-changing diagnosis, just know that there are going to be good days and there are going to be bad days, one doesn't change the others. You just have to roll with the punches.

Gerald: Wonderful. Thank you both for taking the time.

Katie: Thank you.

Gerald: She is active and beautiful

Katie: She is very active.

Gerald: Yep, she's contributed multiple times to our interview, and I appreciate that. It was awesome. I really do appreciate your taking the time to do this.

Katie: Of course, thank you, we appreciate it as well. It helps get the word out, and also, people don't assume that a child will need a transplant.

Gerald: Right.

Katie: And that's been the most difficult thing.

Gerald: Right, wonderful.

Eric: Thanks.

Katie: Thanks so much.