An Orange Socks Story - Nicole and Adam: Spina Bifida

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 today's episode, we speak with Nicole and Adam about their daughter, Piper.

Gerald: Nicole and Adam, thank you so much for taking the time to do an Orange Socks interview with me about your daughter, Piper. It's my honor to learn about her and your experiences with her. Nicole, when did you find out that Piper had spina bifida?

Nicole: I found out at what should have been my 20-week ultrasound, but because she was measuring so small, they pushed her due date back, and it ended up being a 16-week ultrasound, that's when I found out.

Gerald: What were your thoughts when you discovered that?

Nicole: When I first found out, I had a feeling that something wasn't right. During the ultrasound, the technician was asking me a lot of questions about my health. It seemed like she was taking a lot of pictures of the fetus, and then she excused me to the waiting room. It felt like a really long time, and I had a suspicion that maybe something wasn't right. She called me back and said, "You need to meet with the doctor. She needs to go over your results." My mind just immediately went to the worst situation, that something wasn't right. The doctor said to me, "Your daughter has spina bifida." That was the last thing that I heard until a few minutes into what that meant and what the options were when I kind of came to, and I heard the doctor say that she'll need surgery. All I could think of to ask was, "Well, how soon after she is born will she need surgery?" The doctor said, "You should consider in-utero surgery if that is something that you would qualify for." That was something that I had never heard of before, so I was very confused. "What do you mean, in-utero surgery? How does that happen? What does that even look like?" I remember being in shock. I didn't know what the diagnosis meant long-term. It was a term that I had heard, but I didn't know what it entailed, and I was just very confused when I got that diagnosis.

Gerald: What options did the doctor give you? Other than surgery, were there any other options that he discussed with you?

Nicole: The doctor at the time said, "I want you to meet with a perinatologist, a special high-risk OBGYN. So, that doctor didn't give me a lot of options, but did schedule an appointment for me. When I met with the perinatologist, he said, "These are your options, you can abort the fetus, you can see if you qualify for in utero surgery, having surgery on the baby while it's still in your uterus, or you could do surgery after the baby was born." He had some experience with children with spina bifida, and he had seen very good results of in-utero surgery and the children who had benefited from it. Those were the three options that he gave to me, and we discussed each of those options.

Gerald: You decided to have in-utero surgery. Tell me about that.

Nicole: When he proposed in-utero surgery, again it was something I was not familiar with. It was something that was very hard for me to wrap my brain around, having surgery while you're pregnant and then staying pregnant. At the time, there were only three hospitals in the country that were offering in-utero surgery because it was so high-risk, but he said that if that is something that I was interested in, he would put me in contact with the nurse at one of those hospitals. I thought about that and talked with family members and friends, trying to get any information from anyone who had heard about this and looked it up online, Googling it. I felt that this was something I couldn't rule out. He put me in contact with someone at the University of California San Francisco, and I asked a lot of questions to that nurse. "What is this? What does it do? Why do people do it? What are the risks involved? What are the benefits? Why is this something that they offer?" She answered a lot of my questions, and that's when I felt like if this is going to give my baby any advantage, I would do it.

Gerald: And you did.

Nicole: And I did.

Gerald: What were the results of that?

Nicole: The results were better than I'd hoped for. There were complications. I was told worst-case scenario that if I had this surgery, there was a small window for when it is beneficial, and that window is when the fetus is very small. According to my memory, it has to be before 24 weeks, and if the baby goes into distress during the surgery, if I went into labor, the quality of life for that baby was going to be highly impacted, but if I had a successful surgery, the improvements that have been shown with studies are that this child could have reduced need for a shunt to help with hydrocephalus, greater mobility and reversal of brain malformation, which were all things that she was diagnosed with in utero. The benefits that I've seen from that is that she had reversal of her brain malformation. She has surpassed all of her doctors' expectations. Regarding her mobility, we were told the best-case scenario was that she would use a walker or braces to walk for the rest of her life, and now she's running and walking without any assistive devices. There were some complications. Surgery went well, but the healing afterwards did not, and I was in the hospital for about six weeks until she was born in an emergency c-section, so she was born at 30 weeks because of that.

Gerald: Nicole, tell me, what's been the most difficult thing in having a child with spina bifida?

Nicole: It has been difficult accepting that our norm is different. It has been difficult to not wish it were different for us. It's difficult knowing that she will be different from her peers and from her siblings, and that she will have challenges that other kids won't. It's difficult knowing that I can't control a lot of that. I have a lot of concerns that I want to teach her to embrace who she is and embrace her strengths, but I do feel like it's an extra battle because she has differences.

Gerald: Easier question, what are the joys?

Nicole: I feel like I take nothing for granted. When she hits milestones that other kids hit without any additional help, we don't take that for granted. I see my own health and my own abilities in a different light. I'm so grateful for the things that I can do, and I don't take them for granted any more. Seeing her accomplish things brings me such great joy because I know she has to work hard for things a lot of kids can do without any help, and to see her accomplish something on her own brings me so much happiness.

Gerald: That's great. Adam, how old was Piper when you started to date Nicole?

Adam: I think she was three years old.

Gerald: What were your thoughts about dating a woman with a child with spina bifida?

Adam: I didn't know much about it. I didn't think about it until I met Piper and what that entailed. She's just so easy to fall in love with, she has such a personality. It wasn't really difficult. If you understand the expectations, there is so much upside to it.

Gerald: That's great. What's been the hardest thing for you?

Adam: Probably just balancing one physical strength on one side with the other kids who can run a little faster or do gymnastics, and trying to make them all feel special and strong and capable.

Gerald: Adam, you have other children. What has been the impact of Piper on their lives?

Adam: It's like the light. That's the only thing they talk about. They are really excited and ask, "Are we going to see Piper today?" When they are at their mom's house, they talk about Piper all the time. It's remarkable the impact that one person can have.

Gerald: That's super. What impact has Piper had on your extended families?

Nicole: I think everybody loves Piper.

Adam: Roots for her.

Nicole: Everyone takes part in her accomplishments.

Adam: They love to be involved. They say things like, "She is going to dance at the school, we'd love to come. We'd love to see her. We haven't seen her. It has been too long. She's growing so fast." They love being involved in seeing her.

Gerald: If I were to come to you, Nicole, seeking advice because I just found out that my baby was diagnosed in-utero with spina bifida, what advice would you give me?

Nicole: I would say to seek as much information as you can. There are many people who understand what that diagnosis means. There are many different experiences, and there are a lot of different things you can gain from speaking with different people who have that similar experience, that knowledge and that empathy. I had to really consider what her quality of life would be, especially when the doctor said I could terminate if I wanted. When I was weighing that option, I thought that from what I've been told, and from what I've learned about spina bifida, her quality of life is going to be just as great. That was one thing that drove my decision to keep the child and to have in-utero surgery, and I've been so grateful that I did.

Gerald: That's great. Adam, if I were to ask, "Say, I'm thinking of getting involved with a woman who has a child with spina bifida, what advice would you give me?"

Adam: I don't know if it's a direct answer, but it has been great. My kids understand that there are different personalities and different abilities throughout the kids. Our oldest has really befriended Piper, and it has been really fun to watch. They are building tolerance and patience and friendliness to all sorts of people that they might encounter at school. It has been a strength for the other kids as well as those who are interacting with her. It requires patience, because some learning is a little bit slower, but like Nicole said, the reward when she achieves certain things is just so gratifying.

Gerald: Any last thoughts?

Adam: When Piper was born premature, Nicole was in the NICU for two months, by herself. Then she went home on the weekends. She was surrounded by all these doctors for the initial period, so that was a tough time.

Nicole: My perinatologist said, “If you choose to do this surgery, it will take a toll on you mentally and physically, and it might take a toll on your relationship.” It was very hard to be in the hospital on bedrest for two months, and then to be commuting to a hospital that was about an hour away. That was really hard on me emotionally, and it was hard on my marriage at the time, so it was really challenging. I feel like I made the best decision. I’m grateful for what her doctors did for her and what they did for me, because I feel like she’s in a place right now because of the decisions that I’ve made.

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