An Orange Socks Story – Megan and Josh: Apert Syndrome and Hydrocephalus

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I'm so glad that Megan and Josh invited me to their home to talk about their three-year-old son, Edison, who has Apert syndrome. I appreciated their honesty, and I was happy to meet Edison, who is the first person I've ever met with Apert syndrome.

Gerald: Megan, when did you realize that Edison had some issues?

Megan: The second they laid him on my chest after he was born, he looked a little different, but they had used a vacuum on his head, so I wondered if maybe that's why he looked different. Plus, when they first come out, they are gross, so I didn't really know, but they immediately took him away to the table. Then I sensed a weird feeling in the room, like a weird vibe, and I thought, "Oh, crap, something is wrong."

Gerald: What were your thoughts?

Josh: During the birth, I noticed there was something different about his appearance on his face, and then the same thing when they laid Edison on Megan's chest. I could see his hands, and all of his fingers were fused, and my first thought was, "Oh, okay, so he has webbed fingers, no problem, we can deal with this." Then the nurses were cleaning him up, sucking out his lungs and doing different things. I walked over and the nurse said that there were some anomalies. He has fused fingers and fused toes, and his oxygen levels were low, but they didn't know what this was. That was sort of our first view into what we found out later. We actually didn't find out what his syndrome was for a couple of hours. The nurse immediately asked me if I wanted her to call a pediatrician, and I said, "Of course I want you to call a pediatrician," and he came down said that it could be one of two syndromes: Apert syndrome or Pfeiffer's syndrome. He said he needed to go do some research, and within a couple of hours, he came back and confirmed that he thought it was Apert syndrome, at which point we decided to send him to primary children's hospital.

Gerald: What did primary do?

Megan: They just confirmed that he was admitted into the NICU. We saw a geneticist over the next few days, ENT, plastic surgeons and neuro surgeons, and we met a team of doctors. The geneticist pretty much said that we didn't even need to do any testing because he had all the signs of Apert syndrome.

Gerald: What have been some of the challenges that you've had with Edison and his life with Apert syndrome?

Megan: A lot of surgeries.

Josh: The first surgery was at about four months when he had what's called a craniotomy. They had to go in and create a way for his skull to be expanded to make room for his brain. We've done two of those pretty intense, long surgeries. I like to think of it like braces for your head. They put devices on his skull that we had to turn twice a day, and we would open his skull a millimeter every day,

Gerald: Wow.

Josh: He has had all of his fingers released and that was two separate surgeries where they have to do every other finger on the releases to make sure the blood supply is there so they don't lose the fingers. Then we found out just after his first birthday that he had hydrocephalus as well, and he had to have a shunt placed in one of the ventricles in his brain. That has been a complete separate journey so it's never surprising to us now if another doctor says it's time for another surgery. We know that he has multiple surgeries in his future, but it’s also kind of the beauty of what he does. We have great relationships with lots of physicians. We know lots of parents who go through similar things, and it’s nothing that we ever thought we’d experience in our lives, but we’ve learned a lot and made fantastic relationships because of it.

Gerald: Tell me about the joys.

Megan: He is the most happy, pleasant kid in the world. I feel like you couldn’t ask for a better, more pleasant child.

Josh: Our daughter was walking at nine months and saying words, and Edison turns three a week from today, and he just started walking a couple of months ago. He’s talking a lot more, and the sweet things are sort of the things that we celebrate every day with our daughter, but for him, they take a lot more time, more development and a lot more work.

Megan: I feel like when it was time for her to start walking, it was exciting, but when he started walking, we were crying, and it was a way bigger deal.

Gerald: Tell me what impact has he had on your family, your extended family, friends and neighbors.

Josh: That’s a complicated answer, because it’s vast. The first thing we had to learn was to ask for help. For our family, we had to learn how to come together and ask for help, ask my family to watch our daughter when we were going to surgeries. At the end of the day, it has been really amazing to see people come to our aide with the amount of love that people show our son and our family in general. I wasn’t super comfortable being really public with Edison and his journey, but my sister begged me to start a Facebook page for him and write updates any time milestones occurred. It was pretty amazing to see just the number of people who would express emotions or…

Megan: …Interest.

Josh: Interest or love or whatever it was, they wanted to know about Edison. Our family has been remarkable because it’s easy to lose hope in humanity, depending on your circumstances sometimes, and when you have a child like this, you just see the beautiful things in people. You get to see that in your own family, but in other people, too, and it’s a huge blessing, to be honest.

Gerald: What if I came to you and said I had a diagnosis of a child who had Apert syndrome in utero, and I was wrestling whether to keep the child or not; what advice would you give me?

Megan: That’s easy. Even though it’s challenging. the challenges are so worth it.

Josh: So worth it.

Megan: I don’t even feel like it’s a question of is he worth it. He is pretty high-functioning, and he’s happy and pleasant, and he’s just like a normal little boy who has to have a lot of surgeries.

Josh: Yeah.

Megan: There are little delays, but…

Josh: I would tell people that you think you know what the capacity to love is with your first child, or with your second child, or with your spouse, but when you have to care for a child who requires a different kind of attention, your capacity to love is increased dramatically. I would just tell anybody that your life changes in the most remarkable and positive ways. There is very little downside. Yes, we have to watch our son hurt, and that’s the hardest part, but the happiness and the joy and the progress overshadows any negatives a hundred thousand million times over.

Gerald: Wonderful! Thank you.