

An Orange Socks Story – Jen and John: Encephalocele

Interviewed by: Gerlad Nebeker, President of Orange Socks

Gerald: I am glad that Jen and John spoke with me about their son Jackson, who was diagnosed with encephalocele in utero. They were encouraged by medical professionals to abort him, but they didn't and are glad they followed their heart, even after he was found to have multiple physical disabilities after birth. He is a joy in their lives and a delightful child who you will hear making noises during the interview. Jen, when did you find out that your baby had problems?

Jen: It was actually on John's birthday. I scheduled an ultrasound for him. It was on September 25th. and I remember the ultrasound tech looking in, and I just kept asking, "Is everything okay?" She was quiet and just kept saying, "The doctor will come in and talk to you." Finally she went out, and we noticed something floating on the top of his head, so I asked, "Did you guys see that?" Then the doctor came in, and he asked, "Did you guys have some concerns about your pregnancy?" I said, "No, is there something going on?" Then he pretty much drew out the picture and told us that if we did continue our pregnancy, our baby would either terminate itself and not go full-term, or he would have no quality of life if we continued.

Gerald: So he gave you very little.

Jen: Very little. He actually even pulled in a genetic nurse who talked to us as well, who was a genetic counselor, and she gave us the same hopes stating that he would have no quality of life if we continued.

Gerald: So, John, what were your thoughts?

John: My thoughts were, "What's going on?" I look at the facts and the evidence before I make a decision on anything, and I was just dumbfounded by "How can this happen?" They gave us options, and we thought, "Well, this can happen, this can happen, this can happen." We did everything possible because they were said, "You guys have eight days to decide before you hit your limit and can terminate." We did an amniocentesis, and alpha protein test and a genetic test. Everything came back good, so we decided to go on with it and live with the consequences, and I never had a bad feeling during everything going on. I was always the positive one, saying everything is going to be okay. That was tough with everything going on, with every doctor saying, "Oh, you should just terminate your pregnancy. You're not going to have a baby who has any quality of life." It was kind of a tough thing because we had our other daughter Jacelynn with no problems. Then we tried so hard to get pregnant with him, and it was my worst birthday ever. It was enlightening for sure.

Gerald: So Jackson was born, and what did he have?

Jen: When Jackson was born, he actually came out thriving. They told us when we were to deliver him that he would be sent right over to Primary's Children Hospital. He was actually so good that he was in our well unit that whole entire time. He was born with an encephalocele on the back of his head. It did have a little bit of cerebellum in it that was removed. His encephalocele was removed at seven weeks. We found out that he had skin tags on his ears, and one of his ears didn't develop. When they looked at his undeveloped ears, they also looked at his kidneys. He has a horseshoe kidney and a transverse liver. He has five spleens. He also has a pacemaker. When he went in for ear tubes at six months, he ended up going into heart block, and then we ended up putting in a pacemaker.

Gerald: So John, for you, what have been some of the tough parts of having Jackson? Obviously he had lots of things going on, lots of complications.

John: I would say the hardest thing is dealing with everybody else's negativity for what it is and listen to everybody tell us that he was going to have no quality of life. He was going to come out with nothing, and I tried to comprehend that that's a possibility after doctor after doctor after doctor said that we were not very smart for going through with the pregnancy. It was basically us against the world mentality pretty much because everyone was so negative. Even when our own family members found out what was going on, they asked, "What are you guys doing? The doctors say this; why don't you listen to that?" This was not all of the family members, but some. Some were really supportive, but that was probably the hardest thing. Since he's come out, it has been nothing but positive besides a couple of complications with the heart block, but it's just been him defying the odds and doing better and better all the time. He continues to prove doctors wrong, even the ones who say, "Oh, this is not going to happen; he's not going to have this," after he was born. Other than that, it's been really good.

Gerald: That's great, and didn't they tell you that he was going to be a vegetable (whatever the heck that means)?

John: Yeah, they told us at the ultrasounds, "Only two of his limbs are moving, so he might have had a stroke inside the womb that has paralyzed half of his body." He actually went into heart block in utero at 31 weeks, and they almost delivered him eight weeks early. We were at the hospital for three days with Jen on constant monitoring with the heart doctor right there 24/7, and he actually came out of it. They gave her steroid shots to try and get him to grow faster in case we did have to deliver him. Pretty much since he's come out, it has been nothing but positive, positive, positive.

Gerald: And how old is he?

Jen: He is two, and he brings so much joy and happiness to all of us.

Gerald: That was going to be my next question. He's two years old, he's obviously moving all around, and he's very vocal. Tell me the joys that you've had.

Jen: I would say the joys of him; everyday he smiles. He wakes up happy. He is probably the happiest kid, always having a smile on his face. He is loving. He always gives big kisses. I would just say his spirit is so sweet.

John: No matter what, everything he does is always positive. No matter what he goes through, he's always positive. When we were getting the surgery for his pacemaker, the doctor said, "This is so weird. He's in here for this surgery, and he's happy all the time. He doesn't cry and he doesn't whine, he just deals with what he has to do and stays positive."

Gerald: What impact has Jackson had on your family, your immediate family?

John: It brought us together for sure. It was kind of like broken for a little while there, and then when he was born, it forced everybody to come together, and it's been nothing but good since then. He brings everybody together. Everybody is so positive about it. He makes everybody smile. You don't ever see anybody sad with him.

Jen: He's always in a positive mood. He's never crying or in pain or upset. He's just Jackson. He is the sweetest kid ever.

Gerald: So if I came to you with a diagnosis of a child in utero just like you had and were to ask you for advice, what would you tell me?

Jen: I would just show you my son and tell you not to terminate, to continue, and seriously recognize the power of prayer.

Gerald: What would you tell me?

John: I would pretty much say the same thing. Like I said, I'm more of a facts guy, and I would let you make the choice based on what facts you had and just tell you my point of view, my circumstances and my opinion, and then let you make the choice. I would never force any choice on anybody. If you feel like it's in your best interest and the best choice for your family to go along with terminating, then that's on you, but I would suggest not to do that. We had the worst news possible. They told us he was going to come out as a vegetable, no quality of life, and he's the most joyous, happy, fun-loving kid I've ever seen.

Gerald: Wonderful.

Jen: And he is hitting almost every milestone. He's a little delayed, but he will be walking soon. He gets around; he butt scoots. He walks with assistance, and he crawls and climbs.

John: He doesn't talk yet.

Jen: He also does a lot of sign language. He's also profoundly deaf in his right ear.

John: Yeah, he's completely deaf in his right ear.

Jen: And he has mild hearing loss in his left ear.

John: So we're learning sign language.

Gerald: As I was gathering up my equipment to leave the interview, Jen showed me a recent picture of Jackson being held by the physician who told them to abort him two years previously. He was actually thrilled to see him and excited to learn how well Jackson is doing.