

An Orange Socks Story – Janeen: A Grandma’s Perspective: Lissencephaly

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I appreciate Janeen taking time out of her busy life for an Orange Socks interview. I wanted to speak with Janeen and get her perspective as the grandparent of Hunter, who has lissencephaly.

Janeen: We found out the diagnosis when he was about four months old, but we knew something was wrong when he was born. He didn't hold his head quite right, he couldn't nurse, he wasn't sucking, and he didn't look you in the eyes, kind of glanced away. We thought, maybe he was developmentally delayed. We had another grandchild to compare him with who was born five days before, so we would lay them down together, and after about a month or two months, we started noticing some differences between the two. He would arch his back quite often, he wouldn't cuddle, just arch his back. We just thought that this is kind of what he does. I was in a meeting and got a phone call that he had a seizure that day, so I drove up to Primary Children's Hospital, and they were in the ER there for about seven hours. They did a CAT scan and MRI, and had each doctor come in and talk to them, and they had the parents there. They called us all in when the neurosurgeon was there, and he told us what Hunter had, what happened and what his life would be, and that's kind of when we found out. Shock. I witnessed two parents fall to their knees and sob, you know, just sob. We all were crying because it was such a shock. They weren't expecting that kind of news. The doctor told them everything, saying, "He'll never walk, he'll never crawl, he'll never talk." He just told them that he would respond to love. He'll respond to love, so love him, and he kind of hit us all between the eyes pretty hard. It was pretty devastating that day.

Gerald: So Janeen, what was the hardest part for you?

Janeen: Watching the seizures was probably the hardest part at the first. He never cries tears, but with the seizures, he'd cry tears, and so sometimes I'd just cry with him. Not anything you can do while they have a seizure, and those were the hardest to visualize and watch. Feeding him was hard as he didn't swallow until he got the feeding tube. It took a long time to feed him. If you were babysitting him, it would take over an hour to get him to try and take only two ounces of milk. To get him to swallow food just took a while, and he would choke. When you took him for walks, you had to take the suction machine and everything with you. If you took him in the wheelchair for walks, you had to carry all the stuff with you to make sure you had everything with him. The nights were the hardest, if I tended him overnight, he made noises and they just said, "Oh just have the monitor on," and he would choke and sometimes you would run in there. I pretty well stayed up the whole night because I wasn't aware of all the noises he would make at night. It kind of scared me a little bit, so I just stayed up and watched the monitor the whole night or slept on the floor by him in his room. I think those were the hardest parts. He can't talk to you, so when you sit him up on a lounging chair or move him around, you just don't know whether he's comfortable or not. Sometimes he would, you know, give you a face, so you'd know that maybe he wasn't comfortable, but you just try to make sure that he was comfortable.

Gerald: What was your reaction to the diagnosis?

Janeen: What's interesting is I remember the day after the diagnosis. I didn't sleep all night, and I was kind of angry the next morning. I was out on the steps at 4:30 in the morning, and at 5, the sun was coming up, and I was a little mad at the sun for coming up because this was not a normal day for our family. But it was, and your life goes on. I went over to see Bryson...

Gerald: Bryson is Janeen's son and Hunter's father, and Emily is her daughter-in-law and Hunter's mother.

Janeen: I gave them some time and I thought, I just need to go over and see them. My heart was just full as a grandma and a mom. I got over there, and Bryson was laying on the couch by Hunter, and I walked in there and went to kiss Hunter on the cheek, and Bryson said, "See, I told you, you'd get more kisses now."

That's what he said, and I was a little shocked. Bryson said in his heart he knew something was wrong all along. He said when he got the diagnosis, he finally had the peace to deal with it, which I thought was a very interesting comment, where in his heart he felt anxiety and nervousness over something that wasn't quite right and not knowing. He said that he kind of had a peace and a calm. I thought that was an interesting comment. I was up all night, and I'm sure they were, too, but yet, when I got there, I was expecting to see maybe more heartache, but I didn't see that. I thought that was kind of an interesting feeling or thought.

Gerald: What did you observe as the hardest parts for Hunter's parents?

Janeen: The hardest for them at first was just trying to figure out everything. You know, they tried cortisone shots, they tried deciding whether to have a feeding tube and whether he qualified for the feeding tube. He wasn't eating, he was really skinny, they knew he was hungry. He was skinny, and he didn't eat very well. To know that your baby is hungry worried Emily a lot. When he finally got the feeding tube, that worked. It was hard watching them move him around, making sure everything is working, if he's on oxygen, making sure that they were caring for him. They had long nights. They each took a turn every other night staying up with him.

Gerald: Tell me about when Emily and Bryson lived close by you.

Janeen: Well, when they lived here I was their respite. I was the overnight person. I cared for him when he was little and there were just one or two kids, but when they wanted to leave all the kids, that was hard. It took me half an hour to 45 minutes to get all of his meds ready. They're quick at it, they have to crush them. They couldn't get liquid ones because they cost more money, and the insurance wouldn't cover them. So, you have to cut all the pills and crush them; you have to suction them into all the syringes and all of that sort of thing. It took me forever to do all of those things, and the more kids they had, the harder it got for me, and he got bigger. To carry him around was difficult, he's 10 years old, but he's as tall as I am now. He's got tall parents, and so he's tall and dead weight, and he doesn't help you a whole lot. To pick him up, carry him around and move him from his bed to his wheelchair or somewhere, that got hard for me. His seizures changed and everything changed, it was hard. It was getting hard for me to lift him and to handle all the kids, and so just before his seventh birthday, they decided to move to Arizona for the last few years of his life. Here he had pneumonia and was in the hospital all the time, and we almost lost him. He doesn't swallow really well, and he has a lot of mucus. So, they moved to Arizona. I felt very peaceful. I did miss them, but it was getting hard for me to take care of him. So, they moved to Arizona for the last few years of his life to have better weather and climate. He was supposed to live until age five, and he's now 10. It has been wonderful down there. They were able to get services for night nurses, so for the first time in their lives, they slept. I think it changed their lives, having sleep with the other kids. Because of their career choices and their financial stability, they were able to hire two caregivers who come every week. I don't know if they're quite full-time, but they help with the other kids, housekeeping, chores and this and that, so it freed them up from taking care of him all day. That kind of helped, too.

Gerald: Tell about the joys in having Hunter in your family.

Janeen: The joys? When he was little and I would hold him, he had such a celestial face. I would feel peace, and I thought, "How can you feel peace with a child when you know his body is not like anyone else's and it's not going to function?" We found out he was blind, and that's why he doesn't really look at you. But you can see right through his eyes, the joy of taking care of him. His face would light up when he recognized voices or singing. He doesn't as much now as he's getting older and on a lot more medications for his seizures, but he would recognize your voice and just grin from ear-to-ear, so that's the joy right there.

Gerald: What has been the impact of Hunter on your extended family?

Janeen: Some family members were great to embrace it and hold him and love him. My dad has a connection with Hunter and could sit there and sing to him and hold him, and they would both just fall asleep in a chair. Other people didn't feel as comfortable, so that was hard to see. How can you not love a

child like this? How can you not hold him? Other people had to learn how to hold him or how to talk to him. He doesn't respond back, so how do you communicate? How do you do those things? Yet, you can love a child who doesn't communicate back just as much as you can another one. He has changed our lives, and I can't say exactly how he's changed our lives. He's a grandson, he's cute. He's got lots of equipment, so whenever he goes somewhere, it's like packing up a whole house. But he's changed our lives. Will he be missed? Absolutely. To lose a child, it doesn't matter if he has a disability or not. I think the love that you feel is beyond words. He brought us closer together. There were times when you didn't feel close or you felt like, "Wow, what are we going to do? Or how are we going to handle this?" I would go to the hospital and take the nights until like one or two in the morning, and then be at work the next morning because Bryson and Emily needed some time together with their other kids. You look at the challenges that they've had and the money spent and the things that they've had to do. You look at it, and it changed their lives, but I can say that it's all been really good.

Gerald: I appreciate Janeen and her honesty as she spoke of the difficulties and rewards of having Hunter as her grandchild.