

An Orange Socks Story – Emily and Bryson: Lissencephaly

Interviewed by: Dr. Gerald Nebeker, President of Orange Socks

Gerald: I am privileged to have the opportunity to have an Orange Socks interview with Emily and Bryson, the parents of Hunter, who has lissencephaly. Bryson, when did you become aware that your son had some issues?

Bryson: When Hunter was about three or four months old, he started having seizures. We didn't know that they were seizures. He was our first kid, so we didn't really have any comparison. He was a little slow development wise, but then he started having some spasms, infantile spasms or seizures, and we went to the doctor for it. We made an appointment at the children's hospital, but the seizures kept coming, and we didn't know what to do. We ended up at an urgent care facility, and finally we ended up at the ER of a Primary Children's Hospital. That's when we found out, when he was about three and a half or four months old.

Gerald: Emily?

Emily: Well, I think we kind of knew a little bit, because he has a cousin who was born five days after him, and we saw those two babies side-by-side, right from the start. She was kind of starting to focus on faces and smile, so you could see that there was something going on there. But I don't think we obviously had any idea.

Gerald: How did you both feel?

Bryson: It is genetic and it's pretty easy to see on a CAT scan or MRI.

Emily: Yeah, they didn't see anything on the ultrasound.

Bryson: It was pretty devastating, I think, at first. You kind of have an idea, he was our first kid, so you get the nursery together and decorate the room. You think soccer games and just everything else that you've got in your head of how your life with children is going to go, and it was quite a different story than what I had in my mind.

Emily: I think it shattered both of us. It was really bleak too, because what they told us in the ER was that he wasn't going to live very long and that his quality of life would be horrible. I don't feel like the doctor who saw us there left us any room to feel hopeful. We went home feeling pretty shattered.

Gerald: What have been some of the challenges over the years?

Bryson: When he was little, he was a lot easier to care for, and as our first kid, we kind of had the typical parent learning curve that anybody goes through. He was little, and you could take him places, and we just went on with our lives like he was a normal kid. We did the things that we wanted to do, and he went with us, and then as he's gotten bigger, he has required more help. We've had more children too, so juggling all of that is the biggest challenge. He's big now, and it's hard to go places. It's hard to plan family trips or church on Sunday. We do a pretty good job here in the house, but anytime there's something going on, just managing that with the help that we've needed, has been the biggest challenge.

Emily: For me, it's just sensory overload. From the time that he was really little, you could hear him kind of struggling to breathe. He has a hard time managing all of his secretions, and so everywhere you go in the house, you can't be too far away, and you hear him struggle for every breath. You hold him, and you can just feel that his little body is not normal, not healthy. When I look at him, I see all of those things, too, and I feel like, there's all of this stuff all of the time, telling your brain that this child is sick. I feel like the level

of stress that you have as a mom is magnified. When you have a normal, healthy kid who is sick, you just really have to gear up and get them through that, and I think your stress levels are always elevated because there are always these signals coming in from your eyes and your ears and your touch that this baby is not well. Just carrying that around all the time is hard, and then you don't sleep well because you're getting up and moving him around at night, refilling his feedings and changing his diaper, and maybe giving him a breathing treatment. In the last four to five years, the night routine has become more involved, and I think the fatigue and the constant stress that's there over time really can start to make you feel very weary. Like he says, we've gone on to have other kids, and we try to keep up with them. As the other kids have come into our family, you have to find time to sit down and hold him, or do some of the things that you can do to feel connected to him. Trying to find time for that as life has gotten busier is challenging, because when he was little, it was really easy to snuggle him and cuddle him, and now that he's bigger, you think, "How do you bond with this child who is really hard to hold on your lap?" He's getting huge.

Gerald: What have been some of the joys?

Bryson: He's about five feet tall, 58 inches, at age 10. The doctors in the ER that first day that we found out what he had said, "He'll probably live two to five years. Maybe best-case scenario, eight years." And he's 10 years old now. I think we took that and kind of said, "Okay, we don't know how much time we're going to have with him." So, we really kind of dedicated ourselves and cared for him a lot ourselves. We're still very particular in how he gets cared for, how his breathing treatments go, and with his medicine, and we're very involved. I think a lot of that was initially we didn't know how long we had with him, so we just totally focused on him and kind of centered our lives on him. I think that kind of focus has spilled over to how we parent our other kids as well. To have a kid that can walk and run and learn and doesn't have the struggles that he has, it's quite inspiring and it's just amazing. We hold on to all of those little moments with our other kids and we've done a lot with Hunter. After some of the trips we get done and we think, "We're crazy to try and put these together." We go to the beach; he's been everywhere with us and kind of as much as he can be just part of the family and part of the siblings to the other kids. It's fun. Me as a dad, maybe those outings whether it's Disneyland or the beach or grandma and grandpa's house, everything we've done with him, and it's harder as he gets older. But it's been fun to see him. He inspires the rest of our extended family as well to see how they talk about him.

Emily: I think some of the biggest blessings for me have been if Hunter wasn't in our lives, like I don't know that I would know how strong I can be. I think that he shows me every day how to endure things that are hard with courage and grace. And I feel like I can't help but try and walk through this journey of his, here on earth with him, without being inspired by how he faces his challenges and try and do the same thing with him, the challenges that comes with caring for him and loving him. One of the biggest blessings has been to see the goodness and the love and the good things in other people that he seems to bring out. Every single person that I feel like has made a big effort to get to know Hunter and to love Hunter and to serve him in some way has changed me to see that there are people out there that want to reach out and love these special kids just has emblazoned them forever on my heart. I think, really, he's just taught us so much to just appreciate every day, every moment from the very beginning. I love the perspective that I have because he's in our lives, that life is precious and to enjoy the time that you have with the people that you love to the fullest.

Gerald: So, I'm curious, how has Hunter affected the rest of your family?

Bryson: Rockwell loves to push him around when we're out and about, he wants to push the wheelchair.

Emily: Kind of going crazy.

Bryson: Crashing everything and running with him. Yeah, he's kind of the little brother, "Hey, let me go and get my brother and go a little faster than mom and dad want me to go."

Emily: It's been really interesting. I feel like they've all kind of come with their own relationship with him. For example, our daughter Brea, from the time she was a baby, has just been so connected with him. She would crawl over him when she was in that phase, and would crawl up on him and his wheelchair and was so interested in him from the beginning. She's four years old and she still wants to help do his "medies," and she loves to get up on his bed and will push all his medications through his feeding tube and stuff. I feel like we've had kids who just from day one of their birth have been so interested and so in love with him, and other ones that I feel like has taken a little bit more time to cultivate something there. Maybe six, seven months ago, my daughter was doing this read aloud challenge, and she was supposed to read aloud every day for a month. There were a couple of times where she would get up into Hunter's bed and she would read aloud to him. I don't know, just seeing that kind of start to develop between those two has been really cool to see. Where she's just ready for that relationship, for her to initiate those kinds of things. I think they all really like, like Bryson was saying, we've traveled quite with him and I think they all really, here at home it's just kind of like the routine of life, you know, and sometimes I feel like they are more aware of him, and other times it's just like he's here and they're just kind of ships passing. But I feel like when we're on vacation and we're kind of just together as our little family, they're always really sad if we're going to go on a trip and he's not going to come. They're always excited if he's coming, "Oh Hunter gets to come on this trip, it's going to be so great!" They love that.

Bryson: Our kids have developed a lot of patience too because sometimes Hunter needs to stop and we've got to do a breathing treatment or change him or whatever. We could be in the middle of a fun activity that all of this anticipation was built up for and we have to take a half hour break right now for Hunter, and they all react really well to that. I could see other kids, if that wasn't part of their life, just having meltdowns at that point.

Emily: Even here at the house, it's like, "Hey we have to get him ready for bed," or "I can help you in a minute when I'm done helping Hunter." I think it's great for kids to see, hey this other person has needs and I need to wait for a second. You know what else I think has been cool, we're LDS obviously, but I feel like just that whole idea of Jesus Christ, and the healing that he brings is so real for them because they look forward to the day that the Savior is going to come and make our brother whole. They pray for that all of the time. There's just this element that he brings to our home where it makes all of that be very real and come alive because we have somebody that really needs that.

Bryson: Deep understanding for a five-year-old to have. They'll make comments about other people that they see too. We didn't have that conversation ever hit us, we found out after. But we've got opinions on abortion in general, but I think you never know how your life, it's hard to see the future. I think a lot of times, the knee jerk reaction is to be scared, or to think you can't handle it and be intimidated about possibly what that might mean for you and your family down the road. But it's such an opportunity to grow yourself and to go through that challenge and, you know, if you're talking about when you're pregnant, you don't know what's ahead at all. I look at how it's strengthened our marriage and how it's impacted our kids. Looking back, you know, if it were different, I'd be scared to see what our relationship would be like if we didn't have to go through that challenge and choose to come together and grow through that challenge. A lot of times it is a challenge. There are blessings that come with it, but it is a challenge. It can be scary, I can see that, but I think the blessings that have come and the opportunities we've had and how we've kind of lived our life and raised our other kids, it would all be very, very different without Hunter. To have that perspective in making that decision.

Gerald: Thank you so much for sharing so many wonderful details. Emily and Bryson, I'm just curious, what would you tell other parents that find themselves in similar circumstances?

Emily: I think every life is precious, I think that even lives that we look at and feel like they have a diminished capacity for what we consider to be able to do the things that make a life meaningful. We need to be open to whatever that person's story is, and just because they're going to have some physical challenges or limitations or whatever mental, emotional. Everybody brings something beautiful to this earth and to life. It's just, don't be closed off to what that person could bring to the world. I don't know that I feel like I'd be that worried if Hunter hadn't come into our lives, we'd still be doing pretty good. We'd be

happily married and love our kids and everything, but there's just such an added depth and beauty and gratitude and wonder for all of the things that we have that Hunter is the cause of. I think that it's just enriched every aspect of our lives. I think the hard things in life, the hard things that you go through together, that you go through on your own, are the ones that also are the most beautiful and the most meaningful oftentimes. So, I think I would just say, be open to whatever God's story is for you and for your child. What He has in store is inevitably always more amazing than anything you could have imagined, but, don't let fear and all of those things that I think can come with a diagnosis like that, make you shut the door on that whole experience. Be open to whatever that child is going to bring into your life. We're here and we can say that yeah, it's hard, but there is this beautiful side to it as well and you don't want to miss out on that.

Bryson: I think one thing that's helped me and us a little bit is just to have a sense of humor. Everything is very, you're going to doctors, a lot of the things you do seem very, very heavy, and they can be and they are. It's easy to get kind of absorbed in that and feel like you're living your life in a hospital room and doctor to doctor. Having that perspective to sit back and laugh and make fun of a doctor and make fun of your kid a little bit and joke, it's helped. There's times you can't do that, of course, because things are happening that feel very out of your control, but I think that's helped me. You've got to be flexible with a kid with special needs, your life is kind of centered around them, a lot of things are very flexible and to be very rigid, and that's been a struggle for me to say, "Hey it's alright, we're gonna roll with this and see how it goes." Taking a step back and not being so absorbed in the heavy stuff has helped.

Emily: I would just say to other parents out there that are just starting this journey, that you need to trust yourself. Trust your intuition and your instincts as the parents of this child. It's great to get feedback from doctors and therapists and everybody else that's going to be involved in your child's journey but ultimately get on your knees, talk to God, He is invested in this child just right along with you and trust yourself and what you feel like needs to happen. Whatever paths you need to walk down together with your child, ultimately just have faith in yourself and in Christ's grace and in God, that He'll help you to know what is going to be best in treatments and in different things that come up along the way. Just, ultimately, you know them best. Be more trusting of that and not doubting yourself, thinking, "Oh I don't know as much because this doctor is so smart." Take all the good information and weigh it, and that's great, but have faith in yourself.

Gerald: I really appreciate both of you. Thank you so much for taking the time to speak with me today, and for sharing your wonderful story.