

An Orange Socks Story - Brittany and Tyler: Hydrocephalus, Encephalocele,  
Amniotic Band Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I so appreciated Brittany and Tyler welcoming me into their home for an Orange Socks interview about their son, Max, who had multiple issues that were detected in utero. Some of Max's diagnoses included hydrocephalus, encephalocele and amniotic band syndrome. Max lived five weeks after he was born, and his life greatly affected Brittany and Tyler, whose faith helped put Max's situation into a grander perspective.

Gerald: Brittany and Tyler, thank you so much for taking the time out of your busy lives to sit down with me for an Orange Socks interview. I'm honored.

Brittany: Thank you.

Gerald: Brittany, when did you find out that your son, Max, had issues and several diagnoses including hydrocephalus, encephalocele and others?

Brittany: It was at about the 20-week ultrasound. We had a 16-week ultrasound for the gender reveal to find out if it was a boy, but we didn't see any problems then, and he was probably just too small to really notice anything, and it was not the kind of ultrasound that they do at maternal fetal medicine. My OB's sent us to maternal fetal medicine for the big 20-week ultrasound. We were so excited, we've struggled for years to conceive, and we had a miscarriage prior to Max, so we were just so excited to finally get to this point in a pregnancy. We knew lots of people who've had that 20-week ultrasound. The year before, we had seen our sister-in-law's video, so we knew what it was going to be like, and we were so excited. We were just so wrapped up in, "Oh, you can see all of his toes and his fingers, and this is so exciting," and he was moving and it was really great. Looking back now, I can see the tech's hesitation as she was doing the ultrasound, and I can kind of notice the problems. When I was in the moment, I was just so excited. I remember when she was done and took the wand away, she didn't wipe off my belly and didn't clear the ultrasound gel. She just put her hand really gently on my arm, and I got this sick feeling. She said, "I'm not going to wipe the gel off because I'm going to need Dr. Andrus to come in and do a more thorough look. I don't want to take you by surprise, so I wanted to let you know now that I see a lot of problems." She said, "I want to give you that warning. I'm going to have to go see him and talk to him, and then I'll bring the doctor back in, but it will be a little bit so you'll just have to wait here." Then she left us alone in the room, and we racked our brains for what could we have seen that was wrong. We didn't see anything that was wrong, and we were terrified. Doctor Andrus came back in and brought another nurse with him. Thank goodness, she transcribed everything for us because the laundry list was so long and there were so many things they listed off. They showed us everything as they did the ultrasound and kind of went over the things with us. They started at the bottom, showing at

least one clubbed foot, but the way he was positioned, it was hard to tell if they were seeing one foot or both feet, but at least one clubbed foot. They worked their way up to his heart, saying they were not sure what's wrong with it, but it's definitely mispositioned and there's something not right about it. Then they went to the back of his head. We never saw the front of him as he wouldn't turn around, and the reason why was that he had this meningocele or cephalocele. They couldn't quite tell based on his position, but basically there was a fluid-filled sac at the base of the cerebellum at the top of his spine. His head had ventriculomegaly, so the fluid in his head was twice the volume that it should be, and they explained to us they didn't see any brain matter. That's not to say there wasn't any, but it was not visible through this ultrasound. They tried their best to get him to switch positions, I jumped up and down for a little bit, and they pushed around trying to get him to move. They couldn't get him to change positions, and they wanted to see his face to see if he had a cleft lip and palate. That would help us know a little more how all these things would connect, because none of these things seem to match, and they had given us a list of possibilities like he might have...

Gerald: Spina bifida.

Brittany: Spina bifida, thank you. They didn't know, but thought he might have a very rare, serious form of spina bifida. They gave us all this information, and Dr. Andrus was very helpful. He said, "I know this is a lot of information for you guys to take in at once." He gave us this list that they had written out for us to kind of go over some things, and he just said that they were going to need a lot of appointments with us to figure some things out. He said, "I want you to try to come back on Monday. Let's see if over the weekend he'll change positions, and we can get a look at his face or a better look at his head." He said for us to go home this weekend. He said, "I'm also going to call and email colleagues that I have at the University of Utah and at Primary Children's and see if anyone can help me out with this. These are some rare and extreme circumstances that I don't see very often." The last thing that they discussed us with was when they were looking around at him and trying to figure out how all this plays together; they noticed some stringy-like substances around Max. The nurse and the doctor were discussing that and saying, "What do you think those are? Do you think those are amniotic bands?" Our doctor, who had been practicing for over 30 years, said, "I have seen children born who I know had results of amniotic bands after birth," meaning they would have maybe some rubber band marks or maybe some appendages that had been taken off, but he had never seen amniotic bands on an ultrasound before, but that's what he assumed they were. He explained that amniotic bands are fibers that break off from the amniotic sac, kind of like plastic bags getting stuck around fish in the ocean, and would cut off circulation to that area. Based on what he could see, he thought maybe these had wrapped around early enough in development that it caused these problems, but he couldn't be sure. He said, "Let's work one step at a time. We might need to do an amniocentesis to find out if there is a chromosome problem, and we diagnose him with something, and we figure out what we're looking at." Of course, our first question was, "Is he going to die? Can he live with this? Is he going to be

born alive?" He couldn't answer, so he asked us to come back on Monday. We came back on Monday, and we came back on Wednesday, and we continued to come back as they would try to get him to turn around, but they could never get him to turn around. We found out later after he was born that one of the amniotic bands was actually grafted into his cheek and was holding him directly into my cervix.

Gerald: So, he couldn't turn around.

Brittany: He was stuck in that position, poor little guy, so he was actually born with this cute little whisker. They had to cut it to release him when he was born. For the first week or so before it dried and fell off, he had this little whisker that stuck out of his cheek. It was pretty cute, but yeah, that was when we found out everything that was going on with him.

Gerald: Boy, well what were your thoughts?

Brittany: We were terrified and heartbroken. We had wanted a baby for so long, and after our miscarriage at 12 weeks with our first baby, we thought that if we can get past that mark, then we're golden. So, we felt good after that three-month mark, we felt like everything was going to be fine, and at 16 weeks, we found out it was a boy. We didn't ever expect for anything to be wrong, and then it was so much information to take in at once. We were really scared, but we also remember when they left us in the room before they let us go, they gave us some time to get our stuff together and get ready to leave. We both looked at each other and I remember distinctly Tyler saying to me, "I know we are both really scared, but don't you feel really peaceful?" I said, "Yeah," and he said, "I don't know what's going to happen, but it's going to be okay." I just remember feeling that we were going to be okay and that there was this sense of peace, and that we felt comforted in that moment, knowing that no matter what was going happen, it was going to work out, and we were going to be okay.

Gerald: So how long did he live after he was born?

Brittany: He lived for five weeks.

Gerald: Tell me about those five weeks.

Brittany: It was amazing. After that 20-week appointment, there were weekly appointments, MRIs, meeting with neurosurgeons and neurologists and cardiologists, and everyone trying to give us the best chance and figure out what we were going to do. We were given two options. Because we needed to find out if he was compatible with life, we went ahead and did an amniocentesis, and what they found was that he was, and there were no chromosome problems. Based on that, we decided to deliver at the U so that he could be transported directly to Primary Children's right after he was born. Had he not been compatible with life, we could have just delivered at our local hospital and been able to relax and have him for

however long we could have him, but we decided since he was compatible with life, we would give it our best shot and go ahead and deliver there. He was born six weeks early. We had started having distress tests, and they started to notice that he was under distress and the fluid in his brain was significantly increasing in volume very quickly, so our doctor went back and forth. Every time I came in, he would say, "Okay, maybe not today," and he said, "Get ready because I'm just going to make a last-minute decision when it's time for him to be born. I'm just desperate for you guys to have him. I don't want to wait too long and have him be stillborn and have him taken too early and not give him a chance." So, we had less than 24-hours notice that we were going to have him. I had to go back after an appointment and say, "I'm collecting my things. I will not be coming back." We had to go down to the hospital the next morning, and he was born via C-section to give him the best chance. They did not want any risk for him or myself via a vaginal delivery. He was immediately resuscitated after birth because he was not breathing when he was born, and then he was taken to the university NICU and I was taken back to my room. I had yet to see him, but Tyler had been able to see him as they brought him in right as they were pulling Max out, and he was there to give the permission to resuscitate him. They allowed Tyler to go to the University of Utah NICU to see him, so he got to go in there and check on him, and then he came back to check on me. They said, "If he's stable enough, we'll bring him to your room before Primary's," and I was hopeful that he would be. They brought him in his incubator to my room, and I got to meet him for the first time, and it was probably two hours after he was born, do you think?

Tyler: Yeah, he was in the NICU for a while trying to get him stable.

Brittany: So, after a few hours, they brought him to my room, and that was amazing. It was everything we'd been waiting for two years. They brought him in to me, I sat up, and they brought him closer to me and opened up the little door and let me reach in to touch him. He had his one tiny eye, one dysplastic eye they called it, so one eye was small and undeveloped so he really wouldn't open that one very much, and he would just wink at you all the time. So, he opened his one good eye at me, and then he squeezed his hand around my finger, and he was so amazing, and I just couldn't believe that he was here and that he was alive. Our families were there, my parents had left as soon as I told them I was going to be having a C-section. They drove from Arizona to get there, it was amazing. They transported him to Primary's to the NICU, and every day was something new, every day was a new experience. One of the first things they did for him was an MRI. They had done an MRI while I was pregnant, but of course an MRI of him was not the best picture, so the first thing they did was an MRI so that they could tell us what we were really dealing with as far as brain matter and what he had. Within a couple of days, they gave us the results of his MRI and showed us the pictures and explained that hardly any brain matter had developed, that there was a little strip in the front.

Tyler: They compared it to bacon, it was just a little strip of bacon.

Brittany: A little strip of bacon in the front and a little strip on the side, not even really a full strip, and the most concerning part was that his brain stem was missing. They explained to us that your most basic human functions come from your brain stem, breathing, swallowing, all of those things. They explained that without that, there's no way he will ever be able to do those things on his own. We knew going into it that we didn't know how long we would have him or if we would ever bring him home. At some point, we were hopeful that we could have at least some time with him, so we went ahead and made some decisions to try to extend our time with him as best we could. The first thing was when they performed his first neurosurgery when he was...

Tyler: ...like five days.

Brittany: Five days old? Five days old when they performed their first neurosurgery to relieve some of that fluid. They did not do a shunt at that time.

Tyler: It was experimental. Basically, it's a fluid line that they put in his head, and they have to balance the fluid to a beaker so the fluid will flow out, but not quickly or not fast enough. It's a very interesting procedure, one of the perks of being at the U is that they could do those life-saving things that they can't do at the county.

Brittany: Their idea was to see if they removed the fluid, would it stay or would it continue to produce. They tried that first, and the fluid began to go down. His little lightbulb, alien-shaped head began to become the shape of a normal baby's head after a couple of days. After they had done that, and the fluid had started to go down and he had stabilized, they let us hold him finally for the first time. I remember we went in that day, sat down and asked the nurse how he was doing. She said, "Well, do you want to hold him?" I immediately started bawling and said, "Yeah, I can hold him? You're going to let me hold him?" She said, "Yeah, I don't see why not. I asked the neurosurgeon and they said that we can let you hold him for 15 minutes," and so I got 15 minutes that day. They let us hold him, and that was amazing. I didn't know if I would ever get to hold him, and to be able to do that was incredible. Just to be near him was the most amazing feeling in the world. He was so strong and so mighty, and just the power in his presence was remarkable, he was such a fighter. The next day, they let Tyler hold him, and after that, it was just kind of hit or miss here or there, but we could hold him for just in small, 15-30 minute spurts, depending on how well he was doing that day. They had him intubated, of course, because he couldn't breathe on his own. They would turn the machines up and down to see how he would do, and sometimes he would breathe over them, which was beyond any of their comprehension and ours. Sometimes they would have to turn him up significantly when he would need a lot of support. Eventually they did the surgery to put in a shunt, and they explained to us everything we knew about any surgery that if they didn't do it, he'd die, but the surgery could also kill him. Our hope was always that we could get a little bit longer with him. When they did the second surgery, they put in the shunt to help make him comfortable, and right after they put in the shunt, he started to get an infection from the shunt site in his

abdomen. It started to get really red and inflamed, and we got really worried. He got really sick for a couple of days, and they warned us that he could get meningitis from the shunt, and if he does, that will be the end of it. But they gave him antibiotics, and within a couple of days, he was back to himself. He was happy and doing good again, and he was even starting to breathe over his machine. The head doctor was talking about extubating him, and we were excited and terrified because we didn't know how he would be extubated since they had said he would never breathe on his own, so that was amazing. They tried, but he started to get sick again, so they started to turn up the support some more. Finally, we came in one Monday morning, and they sat us down and explained to us that they had done another blood draw which had revealed that his body was full of infection again, that he was developing meningitis and there was no more they could do. They would guide us with whatever we needed, and we could make whatever arrangements we wanted, and when we were ready to turn the machines off, we could. We were allowed to do that, and that was when he was exactly five weeks old.

Gerald: So, he never made it out of the hospital, he was there the entire time. When you interacted with him, you would go to the hospital and interact. That was probably very difficult to have to deal with a litany of treatments and a litany of issues that he had. Tell me about the joys.

Brittany: There were so many despite all the hard things. We always tell people that despite all the hard things, there were so many good moments and good days, like when he would open his one eye at us and we'd say he'd be winking at us, or the first time he ever opened his tiny eye. The first time we ever saw that was when his daddy was holding him, the first day that Tyler held him, he opened both his eyes.

Tyler: He'd always open both eyes when I'd hold him. It was neat.

Brittany: That time was one of my favorites. Our other favorite one was when we had to be gone for a couple of days as I had reached the point of severe exhaustion having been there all day, every day, still recovering from my C-section. Tyler basically had to carry me out of the hospital one night as I could hardly walk, so we decided to come home and rest for a day. Then we had a snowstorm and there was a blizzard, and we couldn't get down to Salt Lake because the roads were too bad. At the time, we had a very old car that couldn't make it, so we missed two full days and that was extremely difficult. During that time, I also went through this, parents in the NICU can totally relate, I'm sure, of wondering, "Does my baby know who I am? Does he know I'm his mom? I'm not there all the time, and he hears tons of voices." We didn't know if he could even see. We knew that the one eye for sure he couldn't see out of, and the doctors were never sure if he was blind in both, so I just wondered if he even knew I was there and did he even know who I was. I desperately wanted to know if he really knew me and his dad. When the snow finally cleared and the roads were good, we hurried down to the hospital. I'll never forget when we ran into the room and immediately asked the nurse, "How is he doing today?" She started to laugh and said, "Well, come over here and ask him," and

as soon as he heard our voices, he started kicking. I'm just getting teary-eyed thinking about it. He started kicking and punching his fists in the air, and he had this huge smile on his face, and he was so happy to see us. When he would over-exert, he had this little air leak in his tube, so he'd make this little squeaky noise. He was squeaking at us, and he was so happy. That was such a special and important moment for me to know that he definitely knew who we were and that he missed us and identified us. That was so special to me because it was only the next week that we lost him, and that was something I desperately needed to know before he was gone. There's something so special about being near a child with special needs. With us, for our faith and our faith in God, we just felt like we were in the presence of someone so mighty and so special with spirit. It was just like being in heaven to be near him. No amount of loss and heartache could ever take away that joy that he gave us, and our gratitude for being able to have five weeks that we really never should have had based on everything that they told us. The neurologist kept saying to us that, "He shouldn't even be able to breathe let alone move," and yet he moved. We just couldn't believe it, it was remarkable, and there is nothing that could take that away.

Gerald: If I were to come to you with a child with a similar diagnosis, what advice would you give me?

Brittany: I feel like I would say to get ready for so much surprise and as much joy as there is heartache, and to embrace it. For us, prayer was significant. Being able to rely on our Heavenly Father was the only way we felt like we could make it through. Just put your faith also in that little child, they have so much strength in them. We felt like our Max had so much strength in him and fought so hard to stay with us and to be here with us, and that was really amazing. I just feel like it's a hard experience, but it's okay, and you'll be okay. No matter what happens, don't give up and don't lose hope. Love the time that you have, because there were days that I was dreading it and days when I was caught up in how sad it was, and how I wished that wasn't the case. There were friends of ours having babies at that time who were taking their babies home. My baby wasn't home, and someone else was taking care of my baby for me. I would get caught up in that, and then there were days I would try to sit back and remember that he's still here and I'm here, and that's all we need. Just try to have that attitude, to not let the bad days get you down.

Tyler: There were a couple of days where we felt just numb, didn't know what to think and didn't know what to do, but you'll always look back on those positive experiences. He was always defying what the doctor said, which always made us laugh, "He won't recognize you, he won't squeeze your hand, and since he's not mobile, he won't wiggle around." Then they had to put bumpers up so he wouldn't roll out of the bed. Those little positive experiences helped us get out of that numb feeling.

Gerald: That's awesome. Any final thoughts or words?

Brittany: Don't give up.

Tyler: Don't.

Brittany: And don't lose hope. Know that they are never going to stop being your child even after you've lost them, and that if you do lose them, you will be okay.

Gerald: Very good, thank you both.

Brittany: Thank you.

Gerald: It was awesome to meet you and hear your story.