

An Orange Socks Story – Alyssa and Ben: Aplasia Cutis Congenita and a Developmental Delay

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: It was an honor to have an Orange Socks interview with Alyssa and Ben. They were young college students who were surprised and shocked when at their 23-week prenatal check-up, it was discovered their baby had issues. The doctor initially thought he had a cyst on his head, and his head was small. Later, a specialist believed it was an encephalocele and told them their baby had a less-than-one-percent chance of surviving, and if he did, he would have no quality of life. The specialist stated that the only thing he could offer them was an abortion. Alyssa and Ben did not make that choice. It turns out that baby Will has a severe form of aplasia cutis congenita and was not only missing the skin on his head, but the bone beneath it, a very rare condition.

Gerald: Alyssa, when did you find out your baby had issues?

Alyssa: It was at 23 weeks. We went in for an ultrasound just for the anatomy scan. Our insurance allowed for two ultrasounds and we had already had one at the beginning of the pregnancy, this was the second. During the ultrasound, our doctor saw a cyst and said what he described as a horseshoe. You could see the skull come around, and then it stopped like a horseshoe, and he was kind of confused and didn't know what was going on. The head measured smaller than it was supposed to, so he sent us up to Madison Memorial Hospital that has more updated equipment where they could have a radiologist look at it and have little bit better scan and discover a little bit more of what was going on. He got the results back the next day, and he called us and said that it was just what he found, that there was a cyst and the head was smaller, and regarding the horseshoe, it looked to them like the skull had stopped growing, but they didn't want to say that. They wanted a specialist to look at it to make sure, so we were referred to a specialist in Idaho Falls. They were based out of Utah, but they have a clinic in Idaho Falls. I think there are four doctors, and they switch off every week and come out and go to Idaho Falls. Our ultrasound was on Wednesday, and Thursday was when our doctor set up the appointment for us to go to the specialist. That appointment was on Monday, so we had a very hectic weekend, not really knowing what was going on. The specialist said that his skull had stopped growing about midway, and that the brain was growing past the skull, and the brain had a lot of defects. They didn't know if there was skin or if there was no skin or a membrane or whatever was there. And they told us that he has encephalocele, that the brain was pushing into a sack. We asked if anything could be fixed and what can happen, and he said that the child had a less-than-one-percent chance of living even past 30 weeks of the pregnancy. We asked, "What about if the baby lives?" He said, "I guess there is a chance, like a little tiny, tiny chance. And if the baby lives, he'll have absolutely no quality of life. He won't move, he won't walk, he may live a couple of hours after birth, and if he lives more than that, he won't do anything. He'll be a vegetable." He said that the only thing he could offer us is an abortion.

Gerald: What were your thoughts about that, Ben?

Ben: I was definitely very, very scared, and I don't think it really hit us. It took a while for it to really sink in that there wasn't going to be a possibility for Will to survive. It was kind of like a slap in the face, but we didn't realize how much until later on, and I think it took us probably at least a week or two before we really felt the full facts, that there would be little to no chance that he would survive. There also was a chance that he would most likely pass away before 30 weeks, so it was definitely very scary and almost not realistic, like not like real.

Gerald: Alyssa, you made the decision to obviously not abort, and then Will was born. Do you want to describe those events?

Alyssa: The doctor said that he'll probably be stillborn around 30 weeks, and then we got to 30 weeks, and then we got to 31 weeks, and then 32, and we kept going, and he was doing great. We met with specialists in Idaho Falls, and then we met with some specialists at the University of Utah Hospital, so we had a couple of appointments where we would drive from Rexburg to Salt Lake. We met with a doctor who was the one who was going to deliver Will, and we planned a C-section with her, and he was planned to be born at 39 weeks and 4 days, or almost 40 weeks. It was a planned C-section and everything was good. We went in, and the attending from the NICU at the University of Utah came in and saw us. The operating room has a little tiny window where they send the babies that need to go to the NICU right through the window. The NICU doctor said that we have life support on stand-by, and we are ready to intubate right after he comes out. She said she didn't expect him to live, and we told them we wanted full intervention so that we could have time with him and then take him off life support afterwards. She agreed, and they had everything ready with the big machines booted up. We had the surgery, and Ben was watching the surgery, and Will came out, and the doctor who said that he would come out blue and not breathing, took him out and suctioned his mouth, and then he opened his mouth, looked at her and screamed and started crying right at her. She was very surprised, and they cleaned him up, and she brought him around the curtain, and we saw his face, and then we saw the back of his head where his brain was showing. They put him in the window and said that once we have him stable, we are going to come back and get Ben. We were sitting there waiting, and I remember telling Ben that it's taking a while for them to come get you, so I don't think it's good. Right when I said that, the nurse said that they were ready for dad, and we thought, "Okay, we've been preparing for this, we are ready for this." The nurse came into my view and said, "Mom, he's doing great, he's breathing on his own, he doesn't need anything, he is doing fine." That's when we started crying, knowing that he's doing fine and he didn't need anything. He was just in the NICU, and they had all these machines booted up to like intubate him and have him on life support, and he was doing great.

Gerald: So, you had made two sets of plans after the birth of Will, what were those plans?

Alyssa: We had a funeral planned, we were going to bury him in Salt Lake.

Ben: We had the plots in the cemetery all picked out, and we picked out the casket.

Alyssa: We would just bury him in Salt Lake after, and then we would like travel up to Rexburg and go back to school. That's what our plan was. We didn't really plan for when he would live because no one gave us hope.

Gerald: So, you really only had one plan.

Alyssa: Yeah, now that I'm thinking about it.

Ben: We had one plan, and then as soon as he was born, we kinda dropped that plan and came up with a new one.

Gerald: With the second plan.

Alyssa: Yeah.

Gerald: Interesting. So everybody was surprised that he was vigorous and he thrived?

Alyssa: Yeah.

Ben: All the doctors were very shocked, especially to find out that there were no other abnormalities or any other birth defects besides just what was going on with his head.

Gerald: What is his diagnosis?

Alyssa: His diagnosis is cutis aplasia, and what's difficult about this diagnosis is that if you look up cutis aplasia, it's the size of a quarter and usually just skin that is missing; bone can still be there or bone is not

there. The way they treat it has a really good prognosis. They let the skin kind of grow in, and they let the bone grow in, and that's kind of like having a soft spot but like a really severe soft spot, I guess. His is bigger than Ben's hand, it's huge, the whole entire back of his head. What goes along with that, too, is that he has brain abnormalities as well, and so with that kind of cutis aplasia, it gets really difficult as to how do you cover that with no bone to cover. Surgery wise it was very difficult and very hard. He wasn't given a good prognosis because of his brain abnormalities and what was going on with his brain.

Gerald: Tell me about your daily routine with Will.

Alyssa: We have two different routines, one is when he is in the hospital, and one is when he is at home. When he is at home, we used to have a ton of doctor's appointments we needed to go to, so that would be our days, just going to therapies and doctor's appointments. He's doing so well now that he is not seeing as many doctors, so a lot of our days just consist of being home and playing and doing therapies together. Ben goes to work, and we wake up, and there are different things we need to do like his G-tube that you have to take care of, and you have to clean his head a certain way because of all of his skin grafts, so he has cares like those that are a little bit difficult, but other than that, it's a pretty normal daily routine that you would have with a normal baby.

Gerald: Ben, what's been some of the hard parts for you, the challenges for you in having a child with a disability?

Ben: I think probably the biggest challenge that I've struggled with is balancing taking care of the family while trying to bring in an income and trying to just to take care of that realm of life while still balancing being there for Alyssa and Will. He has gone through 13 surgeries, and I want to be there for every single surgery, but it's difficult when I only get so much time. Work has been great, they have allowed me to definitely take time off, but not being able to be there for all of his surgeries, even when he has had an emergency surgery, is probably the biggest struggle, just trying to balance that life.

Gerald: Does he need to have additional surgeries?

Ben: Yeah, he definitely will be having an additional surgery in the future.

Gerald: Do we know how many?

Alyssa: No.

Ben: He definitely has some more coming for his skull and everything else for his head, but as for how many surgeries that will entail, there's not really a specific amount. He has already gone through 13 surgeries for skin grafts, and so he probably will be going through quite a bit more at least for bone graft and bone surgery.

Gerald: You're going to try to replace the bone in his head. What's been the hardest part for you, Alyssa?

Alyssa: It's hard to be separated from Ben. There have been a lot of times where he'll go in for an emergency surgery, and I'm alone, and I'm signing, and I think that's the hardest part because when he is in the hospital, we'll walk down with him to the operating room, and I'll sign consent, and then I'll say goodbye, and it's really hard to do that by yourself. It's not that you know Ben's job isn't working with him, but because Will is so complex, needs so many surgeries and has had so many problems, if Ben took off every time, he would be taking off once a week. It's not ideal, I've had to do that alone a lot of the times, and Ben calls and FaceTimes, and we can video chat and everything, but it's really hard to drop your kid off at the OR and sign for consent for surgery by yourself.

Gerald: Tell me about the joys.

Alyssa: Oh my gosh, do you have time? We have so many joys. He goes to rehab for therapies, and at the end of every session, they ask us how satisfied we are with how he's progressed, how you feel he is doing

and how satisfied you are on a scale of 1-10, and we always say 10. With even the littlest tiny progression that he makes, we are just ecstatic about it, and I feel like we wouldn't be like that with a normal kid. We would like be expecting him to develop that way, but with Will, he rolls over, and it's like the best day ever. We are so happy, it's just like you see the littlest tiniest things and it's really fun having him.

Ben: I think it's just really awesome and really exciting to see. When you're there with a child all the time, you get to see a lot of different things as they progress compared to other people who only see the child every now and then. I think that's been the greatest thing, because I was just thinking about that this morning, where a lot of people see him and get to interact with him. When you hold him, he's kind of quiet sometimes. Then during the day when you're just hanging out with him, he is just so energetic and fun to hang out with, and he's fun to be around, and you just get to see a lot of those developmental milestones that he's making in his own life. It just makes it really worthwhile to be able to see that.

Alyssa: Yeah, because they told us he wouldn't interact with people, he wouldn't smile, he wouldn't have any quality of life, and it's fun to see him defy the odds and show his personality because he really does have personality.

Gerald: How has his life impacted your family, your extended family, neighbors and friends?

Alyssa: One of the ways it has impacted us is just to embrace differences and know that it's okay to have a child with a disability. When we were told that Will would have this, it was a sad thing, it was bad, it wasn't good, it was negative, and now that we've had him in our lives, it's like it doesn't have to be a bad thing just because it's different, or just because we don't understand it. It's just that he's different, and it's okay to be different, and it's okay to have a baby who has problems. It's not a bad thing. With our friends, we have seen a lot of service, to go out of your way for people and to embrace differences. If somebody at the supermarket is in a wheelchair, you don't think that's really different, it's just that he's in a wheelchair. It's a normal thing, just a part of society, and then you move on.

Ben: I think in general it has affected everyone a little differently. For us, it has brought us a lot closer. For friends and family, it has been hard for them to see it and transition from how we were because we are definitely different than we were before because of him. It has definitely been a transition for a lot of our family and friends to be able to know how to interact with us and him. It has not always been easy for them. It's not always easy for us, but I actually think in general, it has definitely been a good transition for everyone to have him here.

Gerald: If I came to you and said that at my 20-week check-up, it was discovered that I had a child with similar conditions as Will, and I was being encouraged by the physician to abort that child, Alyssa, what advice would you give me?

Alyssa: I would say you need to give the kid a chance, and I would say every child deserves a chance. I don't want to say that as, "Oh, there, he's going to live and it's not going to be a problem," because there are babies who do pass away, who do have defects and don't live. The point is that it's you who gave them that chance, and they were the ones who chose, or they were the ones who decided to leave, or they were the ones who decided to stay. One doctor that said, "You know, I encourage you to have him at the University of Utah Hospital because everything is there, and if he passes away, you know you did everything you could to give him the best chance. And at the end of the day, you can say that I gave my child a chance whether it worked out or whether it didn't work out." That's what I would say.

Gerald: Ben, what advice would you give me?

Ben: I would definitely recommend that the husband and wife, or even just a mother take into consideration all aspects of the pregnancy. I feel like in general for our situation, the pregnancy was very normal. If we had not had that ultrasound, we probably wouldn't have ever known. In some situations, there may be more risk to the mother, and in that kind of a situation, they really need to take in all considerations from the doctors so they can educate themselves to trust themselves. I know that for us, there were multiple times where we felt this is what we want, but is it really the right thing, and it came down to our making a choice.

We felt good about it, and we had to trust that we were making the right choice and just move forward with that.

Gerald: So, was it worth it?

Alyssa: Yeah, definitely.

Ben: That's one thing that I would definitely recommend for everyone who is going through something like this, it's not just about the parents, and it's not just about giving the child the greatest chance possible. Will has definitely changed people's lives just by coming to earth to be here. It makes me wonder if those things would have happened if he hadn't been there to help influence that. All children who have disabilities are all here for a reason, and they are all definitely here to make differences in people's lives.

Gerald: Thank you both for taking the time to meet with me.