

## An Orange Socks Story - Alie and Tyler: Asperger's syndrome, Anencephaly, and Albinism

Interview by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In this episode, I speak with Alie and Tyler about their three children with disabilities. Their oldest, Jack, has asperger's autism spectrum disorder. Their second child, Amelia, was diagnosed with anencephaly during a 20-week pregnancy check-up, she passed away two days after she was born. Their youngest son, Owen, has albinism and is legally blind. Despite these challenges, or because of them, Alie and Tyler have a positive attitude, consider themselves blessed and wouldn't change anything about these experiences.

Gerald: Alie and Tyler, thank you so much for taking the time to do an Orange Socks interview with me about your three children. Your story is very unique in that you have three children with some very unique issues. Tell me your story.

Tyler: Thanks for having us on here. We really are glad that we are able to be in a community with such supportive people who are going through hard times, but are able to see the happiness in their lives. Alie and I got married about 10 years ago.

Alie: We have three children, and all three have a different diagnosis. Our first diagnosis was when I was pregnant with our daughter, Amelia. She was our second child. We went in for the 20-week ultrasound, and all of a sudden, the technician got really quiet. We were chatting and then it was dead silent.

Tyler: It was just you and her in the room.

Alie: Tyler was in the waiting room because Jack, our oldest, was a toddler, and they said we couldn't have a toddler in there, so I was all alone. They said, "Let's go get Tyler and go upstairs and see the doctor."

Tyler: We kept asking, "Hey, why is everybody acting weird? Why can't we find out if our baby is a boy or a girl?" That's really all we wanted to know. We had to beg and beg to go see a substitute doctor, and this poor soul of a doctor had to be the one to break it to us that they found on the ultrasound that our baby had anencephaly, which is a neural tube brain defect that causes the brain not to form much above the brainstem.

Alie: They wanted to make sure that we knew at that appointment that our baby had no chance of survival. I remember the doctor looking at us and saying, "Would you like to terminate the pregnancy?" As he was saying that, I could feel her kicking inside me, and I thought, "No way, this is our child." I didn't know if it was a boy or a girl. We really didn't know a lot, but we knew enough that this was a spirit inside of me, this was our child, and there was no way we could terminate our child's life. That night we went home and became crazy, Google people and learned everything that we could about anencephaly. It was hard, it was really, really hard.

Tyler: As far as everything we knew at the time, we knew that we were dealing with something that would be life-ending for her, but nonetheless, she was part of our family, and we wanted to try to do the things that could help us bond the best with her, knowing that Alie would carry her for nine months. We knew that she was meant to be part of our family, and that's the thing that really mattered to us. She was more than just the condition that she had, she was a person to us. We wanted to do everything we could to make sure that whatever we could do to cherish that time, we could do that.

Alie: Yes, to honor her life. We loved her at that point. I'd been growing her inside of me for five months. The next day we found out she was a girl, and I knew immediately that her name was Amelia. We spent the rest of my pregnancy bonding with her. It was really, really hard. I remember I spent my 24<sup>th</sup> birthday picking out a casket for my daughter to be buried in.

Tyler: Buying a burial plot.

Alie: It was hard, and right after we found out, we moved away from my family, moved up to the bay area and had to basically start over.

Tyler: We really lost a lot of our family support and our church support. We did it for my work, so I had my work to go back to when I was frustrated or didn't want to think about how sad I was. I had work to go back to, but you were at home with Jack at the time.

Alie: Our son was about a year and a half. People would ask me about my pregnancy, and it was really hard to put a smile on my face and pretend like everything was okay, because you don't want to dump the weight of this prognosis on the lady at the grocery store who's asking about it. When we moved up there, we found our new church community, and everyone was supportive, and everybody just embraced me with open arms. With almost every new friend I made, it was, "Oh, congratulations, you're pregnant," but then I would have to tell them that we were having a daughter, but she was going to die soon after birth. That never got easier.

Tyler: You did meet a lot of people who had gone through similar things. We made good friends with a couple of people who had also lost their children really young.

Alie: Yes, friends who were very supportive and loving. We needed a lot of love at that time, and I feel like despite moving, we got that, and that was really cool.

Gerald: Knowing that Amelia wouldn't survive, Alie and Tyler opted to carry her to term, doing the hard work to get through the red tape to make sure Amelia would be an organ donor for other babies. They were able to meet with hospitals and hospital boards to create a plan detailing the parameters for Amelia's organ donation.

Tyler: People thought we were crazy and that maybe it would be a waste of time, but we kept trying, knowing that it was one way in which Amelia's life could have some purpose for everybody.

Gerald: I asked them if they regretted their decision to carry Amelia to term.

Alie: Not at all. I felt her kicking when the doctor was telling us that our baby had a fatal birth defect and there was 0% chance our baby would live, and I was feeling her kicking inside of my belly, and I just knew that we had to see this through to the end. It wasn't my choice as to when the ending was, I wanted her to choose, and that was important to me.

Gerald: It was a time of mixed emotions. There were babies who needed the organs, and everyone was waiting for Amelia to die, which would happen so her organs could be harvested, yet Alie and Tyler cherished their time with Amelia.

Alie: The doctor had told us that there was a really good chance that she would die during the birth as that is really hard on their bodies because they don't have the cushion along their skull. I feel like she gave me signs all throughout my pregnancy, and I was really scared while I was in labor that I couldn't feel her as much. I was really scared that she was going to die right before I was going to meet her. I remember as the doctor was telling me to get ready to push, I could like feel her kicking me, and I thought, okay, she's alive, and she can't wait to meet us. That was like another sign that she was meant to be ours, and I couldn't take that away from her, she was part of our family.

Gerald: One of the parameters set up by the hospital board was that Amelia needed to live an optimal number of hours after birth, ensuring that the organs to be donated were viable for the recipient. Amelia survived longer than the optimal time window, which meant only her heart valves could be donated, but at least another child benefitted from this selfless donation.

Alie: Throughout all of this, we knew we could help other babies, and we didn't get that it was heartbreaking. That was hard to deal with, being in the hospital with her and wishing she would die earlier so that we could help these other babies.

Tyler: At the end of the day, if we had to choose between the two, I think we are happy that we got to spend two-and-a-half days with our daughter rather than anything else.

Alie: Yeah, we are happy with how it ended up. It was really bitter sweet. The doctor's prognosis was that she would either die before we gave birth or during birth, or she'd live just a few minutes, maybe a couple of hours if we were lucky. When we got two-and-a-half days with her and were able to bring her home, it was beautiful. It was so nice to have all of that time with her, to really bring her in as part of our family.

Tyler: It was crazy getting to the two-day mark and then realizing she could live another hour, she could live another couple of days. We were just taking it as it came. The moment came when we needed to go home and get the car seat, we put her in, realizing the irony of

the situation, keeping her alive with the car seat. We brought her home and cuddled her on our couch, and she lived about 12 hours after that. Those were special moments. We had a photographer there to take a picture right after the birth. We assumed it would be really short, but the photographer was there on and off for a couple of days. We have tons of pictures from the hospital, those pictures are sacred to us.

Alie: It was just a neat experience, really, really hard, but I would do it over again. It was worth it.

Tyler: It's not even to underscore how difficult it was buying a burial plot and burying our daughter in our 20s. We had such great support, and we knew that what we were doing was the right thing. The organ donation didn't really fully pan out, but it was still a great experience, and we met a lot of great people through that.

Alie: Two years later, we had Owen, and it was already an emotional pregnancy. I don't know if you ever feel ready for another pregnancy after you've buried your baby. I was just really scared, and it was really hard on me. I remember thinking after he was born, "Wow, we are going to take a healthy baby home from the hospital." It was just surreal. Soon after we brought him home, we'd be feeding him, and he'd stare at the lights above us, and after about a week, his eyes started wiggling back and forth. I knew deep down that something wasn't right and started pestering the doctors, trying to get an appointment and kept getting pushed off. I kept insisting that something was going on.

Tyler: A lot of doctors would just kind of wave it off. They'd say, "It's okay, babies don't see really great until they are about five-six months old." But Alie kept on prodding him, and to her credit, we finally got an appointment with an ophthalmologist. We were in the hallway, and she came in and flipped on the lights, and Owen immediately shrank back and started closing his eyes. That was her first tip-off that Owen had albinism. Albinism is a condition where your body doesn't produce enough melanin. Melanin is what gives our bodies our skin color. A lot of people notice albino children and people because they have really pasty white skin. It isn't just your skin, the pigment is what blocks a lot of UV rays, so it is also in our eyes and prevents a lot of light from flooding into our eyes. As a result, he has a whole slew of eye issues. I'll always remember that, because Alie and I are pretty light-skinned ourselves.

Alie: We're pasty.

Tyler: We're pasty. The ophthalmologist said that his skin may be normal because we are pretty white ourselves.

Alie: I remember looking at the doctor thinking, well, I was right, something was wrong. I reveled in the fact that I knew something was wrong, and that soothed me initially, but then I realized that we were dealing with something that would last for the rest of his life. That was a heavy weight to take on, especially two years after we lost our daughter, so I kind of felt slapped in the face by God. I was angry. I was supposed to be getting this perfectly healthy, normal child, and I didn't.

Tyler: It's hard as a dad to hear that your little boy won't likely ever be able to hit a baseball or do normal sports things. A lot of them aren't impossible, but some of them, like playing baseball, can be very difficult for him.

Alie: It's difficult, but it's not impossible. If he wants to try baseball, we will not hold him back from that, but he does have different things. He has depth perception issues, nystagmus is where his eyes wiggle back and forth all the time, all day long. Strabismus is when he tilts his head to try to focus his eyes. Once we got over the fact that our child has this life-long disability, did all the research, grieved the loss of the child that we thought we would have and just accepted this as our new normal, things got easier, getting a hat and sunglasses and sunscreen every single time we go outside.

Tyler: Once he got his glasses, a lot of people saw outward changes happening to him, and they just assumed that he was getting better and was just going to grow out of this and be normal like all of the other kids. It was hard to explain to all of these people that what he has is a disability, and he's always going to have limited vision. While we're always going to be there helping him to work around and to do the best with what he has, his abilities are different than ours in some ways.

Alie: He couldn't see our faces until he was five months old, and that was really hard on me emotionally. I felt like I was a wreck, but once he got glasses at about six months old, he started seeing us more. His vision was definitely different. He's legally blind. We had a lot of hurdles to overcome, but glasses made all the difference along with a support system of educators around us. We found the right doctors, and he ended up getting surgery.

Tyler: He was about two years old when he had the opportunity to have a surgery to help with his eyes that just swing back and forth with nystagmus. He came out just great through the surgery, and we would say, "Hey, Owen, can I see your magic eyes?" He'd walk up to you and pull up his glasses just above his eyebrows, and then look at you intently, like six inches away from your face, and you could see his eyes more still than they were before. He was so content with himself, and it was amazing to see that even with a two-year-old child how much of a difference a procedure like that made for him.

Alie: We love calling his eyes his magic eyes. He's just a very happy little kid. He's charming and so much fun to be around.

Tyler: He adapts really well. He has a great memory. I like to think that some of that is because he doesn't see so well, so he absorbs things that you tell him like a sponge.

Alie: We feel like his other senses are a lot stronger. Sometimes we are nitpicky. We see the times that he'll just walk off of a curb and not realize that there was a drop-off, or he'll trip or run into things. We see all of that, but in the end, it's our job to be as supportive and loving as possible, and we are trying to give him every opportunity. We are trying to get him through school, and we are going to try to get him to learn braille, and right now he's also doing cane training.

Tyler: Which he is very excited about.

Alie: He's very excited about using a white cane, so it's fun to see how we've all embraced his albinism. When he was a baby, I was in that grieving process, and I wished every day that he didn't have this and that it would just go away, and, "Why us? Why us?" Now my perspective is totally changed, I couldn't see him any other way as it's just who he is.

Tyler: That kind of takes us to our oldest child, Jack.

Alie: When Jack was around one-and-a-half to two-years old, we started seeing some differences in him. He was evaluated for speech, so we did speech for maybe three or four years. His struggles were unique from other kids, what his peers were going through was usually not what Jack was going through.

Tyler: It was really hard, because he is a really happy kid and also really smart.

Alie: He taught himself to read, but we noticed that his interactions with his peers were different. He struggled a little bit socially, and we finally got the diagnosis of asperger's.

Tyler: By that time, we thought, "Okay, third time around, we can handle this." But it's troubling for us that this was under our noses the whole time. It made it a little harder emotionally because...

Alie: We felt like we missed something.

Tyler: Yeah, we felt like we missed something and that we could have helped him earlier. At the same time, we already felt emboldened because we knew that we could help him, we knew places we could look, and we knew the network was there to help.

Alie: Third time's the charm, we got this. We shed a few tears driving home from that appointment, then it was off to real life. We've been through two other diagnoses before, this third one is not going to break us. I'm supposed to be his mom.

Tyler: We didn't get that diagnosis just so that we could apply a label to him, we got that diagnosis so that we could learn how to help him. We know another family that I grew up with who had a child with some behavioral issues, but the family tried to hide it and push it down. We look back and wonder if it would have helped him to know or not know, would he have liked to not have that label applied? Would he have liked to maybe have the label, but also have a network of people to help him who understood what the label meant and who were equipped to help him overcome the obstacles that he had?

Alie: So, spoiler alert, we like to know. We like more information; we feel empowered with information. We feel very strongly as a family that it helps our kids to know their diagnoses, so Owen knows he has albinism, and Jack knows that he has Asperger's, and it's just very factual. This is what it is. It opens up doors for us to talk about it and normalize it, because this is our normal.

Tyler: The more our kids grew up and the more that we grew up, we realized that everybody has their own story, too. Some people have very visible stories. Owen's is pretty apparent when you see him outside with his hat and sunglasses, especially if he has his cane. He has something that he's working through, and some people have things that are less visible.

Alie: The disabilities we have with both of our boys are a lot less visible than other people are dealing with.

Tyler: Our kids know that they can do anything that they can put their minds to. They know that some things they have to work hard for, and that's life, and life's hard for different people in different ways. Jack wants to feel loved, and we don't want to brainwash him to fit our mold of a normal person, but we want to help him so that he can be self-aware and learn how to be himself while also understanding how that affects other people.

Alie: Yes.

Tyler: The big thing for him is understanding how other people feel in reaction to what he is doing.

Alie: Yes, we have to teach him feelings, and that was something that we noticed when he was little, he's not quite understanding...

Tyler: ...what it's like to be angry, to be anxious, to feel sick, to feel happy.

Alie: We kind of saw a disconnect there. Now he's seven and a half, and we have a feelings book. I wrote down a bunch of different feelings, and it has pictures of kids around his age expressing each emotion, so if it's anger, it's a kid with his hands on his hips making an angry face. Then we write the definition, and we fill in a sentence of times that he has felt that emotion, and that's something that's been so helpful for him.

Gerald: You have had three children with very, very different disabilities. What advice would you give to another parent who may have multiple children with disabilities?

Alie: Don't be afraid to parent your children differently. You need to adapt to each specific child. Going into parenting, I thought I was going to treat them all the same. You want to be fair, but it's not possible. Jack has more of a cognitive disability, and Owen's is more of a physical disability. Being aware of that and accepting the fact that as a parent, sometimes we have to be flexible. That makes all the difference, and it has made a huge difference in our family and our routines, the boys are accepting of that, too.

Tyler: My engineer brain tells me that rather than looking at it as a label that you apply to people, you really think about a symptom and a fix. Rather than looking through the lens of "Owen has Albinism," let's find some fixes. "Owen is tripping over the curb, so how can we help him not trip over the curb? What's the cause of that, and how can we help him to do that on his own?" You have to take a lot of extra care to teach them no matter what your

child can or can't do. They actually can do a lot, and chances are they can do more than you'll feel like they are able to do when you first find out about your child's diagnosis.

Alie: Oh, yeah, you think the worst in the beginning.

Tyler: You fear the worst, and really it ends up being a little bit better than that, and it will surprise you at times. Sometimes the problem is that your anxiety and your nervousness will project onto the child, and they will feel nervous about those things. You have to learn to bridle that and let them experience things. You don't want them to not do something because...

Alie: You're afraid of failure as their parent.

Tyler: Because of their title, or because you're afraid they will fail. You want them to do it and find out that it isn't good.

Alie: We are still learning that obviously, if Owen wants to do baseball, we are going to have to let him try it.

Tyler: This fall is going to be pretty interesting. We are going to put him in soccer, and we're hoping that maybe the bigger ball and the fact that when you're four years old, soccer is like a mob mentality.

Alie: Yeah, everybody is crazy.

Tyler: He can probably follow the mob pretty well, so we'll see how it goes, and we'll listen to whether he likes it or not, because at the end of the day, if it's really hard for him, it's not like he's just going to cry on the field. He's just going to lose interest, and that's okay. The trick is finding the things that he wants to do. It's certainly empowering to help your kids work around these things, see how much they learn and see how happy they are doing things that they see other kids doing or that you can do with them.

Alie: Just laughing through it is how we've gotten through. By the third diagnosis, it was okay, well, this is just our family. We are going to be unique and own it, and this is us.

Tyler: A lot of these things are sorts of things that really apply to all children. We noticed that the things that we've learned with Jack, for example, are things that have helped Owen a lot, and they've helped other children around us. The things that we do for these precious children with special needs are things I wish I knew all along so that I could help people. They really help you know how to help other people around you and identify people in need. Just remember the way that you feel when you're around these precious children and think about the people around you in a different way, because a lot of us are intimately connected to our children and the struggles that they face. Sometimes we don't see, and we are insensitive to the people around us and the struggles that we don't know.

Gerald: I appreciate being able to get to know you guys a little bit and your family. Your story is interesting. I have interviewed families that have had multiple children with disabilities, but they are typically the same disability. Yours are so unique, and your story is terrific. I want to thank you for taking the time to do this interview with me, so thank you both very much.

Alie: Thank you for having us.

Tyler: Thank you.

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