

An Orange Socks Story – Traci and Mike: Semilobar Holoprosencephaly

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: Traci and Mike met with me for an Orange Socks interview regarding life with their son, Liam, who has semilobar holoprosencephaly. He also had a cleft lip at birth that has subsequently been repaired. Liam is a twin, and his brother has no disabilities, surprisingly. Traci and Mike were encouraged by a specialist to abort the pregnancy because of Liam's diagnosis which, of course, would have ended the life of both babies. I'm glad Traci and Mike did not follow that advice. I got to meet the brothers, who are now five years old. What a privilege! Liam stayed for the interview, in fact, you can hear him making noises in the background while his brother had more interesting things to do downstairs. Liam is delightful with an ear-to-ear smile that lights up the room.

Gerald: Traci, when did you find out Liam had a disability?

Traci: When we got pregnant, we found out we were going to have twins, so naturally we were being watched a little bit more closely. We had to go through some fertility treatments, so our journey started really early in the pregnancy. At 14 weeks, we found out what we were having, and at 16 weeks, we went back just because they wanted us to come back every couple of weeks. While the tech was looking, we were still goo-ing and ga-ing over our two little boys because we were surprised we were having two boys. I thought there would be a girl in there, for sure. Then the tech kinda got quiet and said, "I'll be right back. I have to go grab the doctor." I gave her this look like, "Why? What's going on?" All she said was, "I see something with the brain," and I think she mentioned the clefts, and then she got up and left. I looked at Mike and just started crying because obviously something was wrong. It was a while before the doctor came in to talk to us, and he explained that they thought he had agenesis of the corpus callosum, that the corpus callosum was missing, and they also saw the cleft palate and the cleft lip. They sent us to a specialist, and he looked at it and confirmed that it might have been this. Then he started at that appointment, because he was from Colorado and was just kind of visiting, and he started talking about selective birth or different things like that. We thought, "Why are you even talking about these things?" He was just letting us know that there are options, and I'm thinking that I have another baby in there, and as far as we know, he is completely healthy, so why are we even talking about this? That was interesting for me. Then they sent us up to the university where we met with a specialist. We were still thinking that it was this agenesis corpus callosum, and we could just be delayed with different things, but we could still live a normal life from what we could understand. Then that's when they came in and shared this huge word with us, and started talking about it, and all I remember really is asking, "Will someone write down this word? I have no idea what you even said to me, and if I can't even pronounce what my child has, how am I ever going to be able to comprehend it all?" At 16 weeks in, we saw that there was something to be concerned about, and then there were concerns that he had Trisomy 13 as well, but we decided to not go through with the testing for that because if something went wrong, it could then happen to Logan at the same time. We just felt like they could give us knowledge, but it's not going to change the situation, we are still going to carry these babies. We decided not to take the risk, and then when he was born, we found out he didn't have that, so it was probably good that we didn't take that risk.

Gerald: Mike, what were some of your thoughts during this time?

Mike: I'd say once we found out, obviously there was concern and confusion. "What do we do?" was a big question. "What does this mean? When we deliver, will he be stillborn? Will he survive?" I had the concern of how or if it would affect his brother, so just a lot of questions. There was nothing to do at the time, so we decided to just move forward and see what happens.

Gerald: What have been some of the challenges or the hard things that have come with your son and his disabilities?

Mike: When he was young, he would not sleep unless he was being held, and not only held, but bounced. My wife and I would take shifts. I was going to school full-time and she worked full-time, so I took the night shift or I took the day shift when I wasn't in class. I took some night classes and let her sleep at night. I'd take him until about 4 in the morning, and then Traci would get up and take him until about 8, when I would take him as I went to school, so that was a big challenge.

Traci: There was exhaustion and lack of sleep. He was so little that they couldn't make some of his medications small enough to give to him, so we would have to mix them and give them to him through a shot. We would have to do that a couple of times a day, so besides being new parents, we were learning, and this was outside of having another baby.

Gerald: I was just going to ask that, because you didn't have just one child, you had two, and twins at that, which is difficult enough.

Traci: We were exhausted. People would ask how we were, and I would say, "We're fine," but I didn't realize how exhausted I was until we started getting rest again. It took a good couple of years doing that whole night shift and morning shift. Then when Mike got done with school and started working, we just did every other night. One night, I just wanted to sleep, but then the next night I got to sleep, and the same thing for him. Liam couldn't self-soothe, and so he had to be held and talked to and rocked. He couldn't just hang and chill, and so he was either held and happy, or not held and upset.

Gerald: Traci, what are some of the routines that you have to do on a daily basis to care for Liam?

Traci: Liam doesn't take any food by mouth, so he has a feeding pump, and he gets multiple medications throughout the day. There are those routines to make sure he gets his medication and his feedings. He's non-verbal, so he doesn't communicate as to what he needs, although he definitely communicates through his eyes and through his face. It's like caring for a baby, honestly. He's a five-year-old kind of baby, and in a sense, caring for a baby is similar to caring for him.

Mike: Yeah, there's problem-solving, whether it's needing his diaper changed or is he hungry or does he just want to be held or does he want to be moved or readjusted...

Traci: Does he want to play, is he bored or is he over-stimulated?

Mike: Except he's the size of a five-year-old.

Gerald: Tell me about the joys.

Traci: Like you saw when you first got here, his eyes are very expressive. Even as a baby, he had the biggest eyes. You can see in the pictures that it was a pretty severe cleft lip. It was a bilateral cleft lip, so cleft on both sides, and it was turned and attached to his nose. But that was just my baby, and I fell in love with that face because when he smiled, his lips would just flare and be open. When he went in for surgery, I was really sad and scared for his face to change, thinking he wouldn't look the same to me. But he had those big eyes, and he kept those big eyes, and that is like his line of communication. It's just his eyes and his face, he just lights up, and he lights up a room. He obviously has a good sense of humor.

Gerald: Now he's laughing.

Traci: We were remembering those early days, too. He talks his little jibber-jabber like a kid does, but he does give and take, too. He'll have a whole conversation with you. People just light up when they see him. It's not just Liam either, it's Liam and Logan's relationship together. Lots of people come up to me and say, "Oh, my gosh, I have tears in my eyes just watching your boys" because there is just this special bond and spirit and feeling to be around them. He's kind of our calmer. Everyone loves him and fortunately, he is the favorite of everyone in the family.

Gerald: Mike, do you have some joys that that might be different from Traci's?

Mike: Joys are when he's not sad and upset, which luckily isn't as often as it used to be. And his expressions, just visually how he makes them his own and how he communicates with us. We're continually learning new ways of communication with him and allowing him to let us know of things he needs or wants. Something recently that we've learned is that he has understanding and can be taught things, which she'll want to show you later.

Traci: Yeah, I'll show you.

Mike: Unfortunately, he can't see that over audio, it's all visual to see, so sorry listeners.

Traci: But it's the most amazing thing for me.

Mike: That's probably the biggest thing that's happening right now. It's a lot of the same things Traci said. He's a part of the family, and as the oldest by a minute, he does look after his brother. It's kind of fun to see how he cares for him, not only as Logan cares for him, but as he cares for Logan. Those are good things, and seeing him grow and improve, and still be alive and not having too many extra healthcare problems so far is good.

Gerald: Good. What impact has his life made on your extended family?

Mike: Like Traci said, everybody loves Liam, whether it's friends or strangers or, of course, family. They all love him. He's a member of the family, and the more everyone gets to know him and they build a relationship with him, they really see that Liam wants that.

Traci: People are just drawn to him.

Mike: They really are, though first impressions can be different for others, but once they've met him and see him and talk to him and develop a relationship with him, everybody loves him.

Traci: Mike's mom gets really stressed out, and when she needs to have a moment to relax and just needs to have some peace, she wants to be with Liam, so she'll call.

Mike and Traci: I need some Liam time.

Mike: I just need to hold Liam and let him share his peace and relaxation.

Gerald: That's cute.

Traci: She's a couple of hours away, and when she's stressed out, she'll call him and ask, "Can we come this weekend? I just need to be with Liam." He just puts things into perspective for you. I think people see that. He is seriously so happy. I guess one of the things I struggled with at first was my feeling sorrow for what he couldn't do. I had a really good doctor, and she's like the first one who really sat me down and just talked to me and asked me questions about how things were going. Then things came out that I didn't know I was feeling, and a lot of it is just sadness that he can't do this and he can't do that, and will he ever be able to do this. She pointed out to me that he doesn't have that sorrow because it's not that things got taken away from him. He's happy, and he feels loved, you can see that in him. He's not sad or feeling sorrow the way we feel sorry for him, so I'm trying to learn to not feel sadness for him if he's not feeling it for himself.

Gerald: It would be very easy to compare the two boys, right, because of their being twins.

Traci: For me, it wasn't so much seeing Logan progress and do things because I knew Logan would do that. He was going to grow and be bigger, and he's going to be able to do all these things. It's when friends or family members have had babies a couple of years later and they are doing things past what Liam can do,

and they were crawling and rolling, and I felt more sadness that he couldn't do those things, but it's all right.

Gerald: If I came to you and had just gotten news that I had a baby with a diagnosis similar to Liam's...

Traci: That's a hard one, because I think what we struggled with a lot was that there's not this defined path that he's going to take. There are so many different scenarios because it's with their brain. So, I would tell someone that as you're a parent, you're going to get to experience their journey, and it's a personal journey for them. Give them that chance. It's going to be hard, and you're going to have to learn a lot, and you're going to have to be okay with not understanding a lot. There are even a lot of things that he does now that we don't know exactly what it is, and it's just one of Liam's things, and you just have to be okay with that. People can see him as my greatest trial, but it's a trial that brings me happiness every single day, and I don't think there are a lot of trials out there that can bring you happiness at the same time. It's not easy, but our lives are so much more enriched and full having him here, and the experiences we've gotten to have in life are so full. We miss out on a lot of different things, too, and that's an adjustment, but I think it gets made up for in other ways. I'd say go for it.

Gerald: Is there anything you would add to that, Mike?

Mike: There will be hard times, but there will be very happy times and as joyous times as a typical child.

Traci: Yeah, he's our easy one, by the way.

Mike: He was the hard one, and now he is the easy one. He's not sassy and doesn't talk back or thinks he's in charge, he knows he's in charge.

Traci: Yeah.

Mike: There are lots of things that you will question. You'll go to the internet and use whatever search engine to try and learn more about it. When we found out, that was some of the first things the nurses told us, "Don't look up images on the internet as it will scare you." But like Traci said, it's very different for every child that is diagnosed with this has a completely different path. There are a lot of children who are stillborn, who will never make it, and some that are, how old was the oldest one you saw?

Traci: I met one in her 20s, and there was another guy that was in his 30s.

Mike: It can be completely different. We met another local kid who had the same diagnosis, and he was five or six at the time.

Traci: Yeah, and he just turned 10.

Mike: That was five years ago, and if you put them side-by-side, compared to where the other boy was, his family was very surprised when they met Liam to see how happy he was and facially expressive, making eye contact and those kind of things, and you could see they were impressed by that. I don't know if they felt sorry or bad that their son didn't provide that, but they know Jackson as being like that.

Traci: There are different medications they are on, too, so it's hard because there are so many different variables with it. Liam is definitely our social little guy, and I see him always being that way.

Gerald: Well, I'm glad you had him here with us so we could meet him and interact and get some of your noises on the recording.

Traci: He's glad he was here, too. Probably made it a little noisy though.

Gerald: Well, thank you.