An Orange Socks Story – Sariah and David: CHARGE syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was happy that Sariah and David were able to meet with me to talk about their son, Spencer, who has CHARGE syndrome. I was very glad to meet Spencer, who is now 17 years old. He is deaf, visually impaired and concurrently taking high school and college courses.

Gerald: Sariah, when did you find out that Spencer had issues, and what were some of the early challenges?

Sariah: We found out that he had some birth defects within about four or five hours after he was born. We didn't get an official diagnosis until he was 11.

Gerald: Wow, what type of defects did they diagnose?

Sariah: The first thing they found was a tracheoesophageal fistula, or TEF for short, and that needed to be repaired pretty darn quick, so he was life-flighted four hours away from where he was born. It was the first 24 or 48 hours. I wasn't there, my husband went with him. I had a C-section, so I had to stay in the hospital.

David: He was born early in the morning, and then that night he was…

Sariah: …had his surgery.

David: No, that night he was life-flighted to UCLA, and by the time I got down there in the morning, he was already in surgery, so less than probably about 24 hours after he was born, he was having his first surgery.

Gerald: Holy cow, and you mentioned that they didn't have a definitive diagnosis until he was 11?

Sariah: Till he was 11.

Gerald: And what was that diagnosis?

Sariah: He has been diagnosed with CHARGE syndrome. Each letter in the word CHARGE stands for a different birth defect, so it's kind of an umbrella term for a bunch of things. You can have a clinical diagnosis, or you can have a genetic diagnosis, but it basically all means that you treat it all the same way. For him, it's a clinical diagnosis. We did not do the genetic testing because it's expensive, and it wasn't going to change anything, and I would be surprised if it was genetic for him.

Gerald: What types of issues? You talked about the first one that took surgery.

Sariah: He had a total of three surgeries to repair the TEF, getting all his plumbing straight. Essentially with the TEF, the esophagus and his trachea are supposed to form one tube that then splits into two, but his didn't split all the way, so he had a connection between the two tubes. He also had a blind pouch, so his esophagus grew down midway into his chest, and then turned around and grew into itself, so he had no connection to his stomach at all. That meant that if he took anything orally, which in infancy would be all liquid, it would have gone to his lungs and he would have drowned.

Gerald: Oh.

Sariah: So that was not really a good thing. He had to have all of his plumbing re-done so that it all went to the right places, and that took three surgeries over six weeks. He had three major surgeries in six weeks, and they placed a feeding tube, and then for the next six months, every two weeks he went for an overnight procedure for dilatation where they would stretch the esophagus and try to minimalize the scar tissue so that he would have good function. He has had a lot of surgeries and a lot of work.

Gerald: He’s also deaf or hard of hearing?

Sariah: He is deaf, and he has a vision impairment, and that is common with CHARGE syndrome to have all of those things.

Gerald: Okay.

Sariah: A lot of kids with CHARGE syndrome will have a cleft lip or cleft palette. TEF is really common for heart problems, growth issues, hormonal issues and hearing and vision problems.

David: Heart.

Sariah: I said heart, I’m forgetting something.

David: Genitals.

Sariah: Gastrointestinal, endocrine, all of those things.

Gerald: Okay, so David, what have been some of the challenges in having Spencer, and what are some of his issues?

David: I guess a lot of it is not knowing what to do for him. Initially, it was just trying to be supportive of him and my wife as she is trying to be supportive of him. And being in the hospital a lot while he was bored, and worrying a lot that there are going to be other issues pop up as he was growing up. One of the biggest ongoing challenges for me has been learning sign language. For the first half of Spencer’s first year, I was in school, and I was focusing on that and didn’t take the time I needed to learn sign language, so sometimes communicating with him can be a challenge. The other thing that is a challenge is just knowing what he’s going to be like. Because of his TEF, he had a hard time swallowing, and sometimes if he ate too quickly, he would get stuff caught in his throat, and if we couldn’t get it out, then he would have to go to the hospital, and they would have to go in and scope it out. That was always stressful, just trying to make sure he is eating properly is probably the biggest challenge.

Gerald: Do you have other challenges you’d want to add, Sariah?

Sariah: That one in particular gets better as they get older. It stretches out, and the scar tissue isn’t so full, so food passes through easier. The younger years were hard probably until he was about seven or eight-ish. We were in the hospital just to have food removed from his esophagus.

David: At least once a year.

Sariah: I’d say more than that, at least quarterly.

David: Yeah.

Sariah: At the very least, four times a year, if not more often.

Gerald: How old is he now?

Sariah: He’ll be 17 in a couple of days.

Gerald: Easier question, Sariah. What have been the joys?

Sariah: He has this amazing ability to love everyone regardless of how they are, who they are, or how terrible they treat him. It doesn’t even phase him. He just loves everybody with this amazing love that is a good example, so that is really great to see. He does really hard things, and he gets really exhausted. Part of CHARGE syndrome is poor muscle tone. He has hypertonia, so it takes him twice as much effort to do what everybody else does, and he just does it generally without complaining. He never misses a Boy Scout hike. He is very involved in scouting or a camping trip, even though it wears him out, and he crashes hard at the end of the day. He'll be the last one up there, but he will do it without complaint, he loves it. A few summers ago, he did a pioneer trek, and even though he had to slow down and be the last one at the tail end of the group, he did it. He likes doing that stuff, and he enjoys doing it. It took him years to learn to ride a bike, it was hard because of his vision impairment. He doesn't have depth perception.

David: Balance.

Sariah: …or good balance, so learning to ride a bike was really hard. He probably was 10 by the time he really mastered riding a bike.

David: He still hasn't mastered it.

Sariah: He is still a little bit wobbly.

David: Still struggles a little bit.

Sariah: But he can finally ride a bike, and he never gave up. He just putts along. He is determined.

David: With something like learning to ride a bike, he was never afraid to fall down, because he would always just get right back up. He never let his disabilities keep him down. He's always just gotten right back up and kept going at whatever it was he kept wanting to do.

Sariah: Yeah.

Gerald: That's great. What are some joys that you've experienced, David?

David: He is just one of the happiest kids you'll ever meet despite all these things. You look at his life, and you think, "Wow, that's gotta really suck," and he is just the happiest kid you know. Like Sariah said, he is always trying to be friendly with people, and he doesn't let other people's thoughts about him keep him down. He was never really bullied at school, even though you'd think that someone different like him would be a prime target.

Sariah: He was for a very short amount of time, but the bullies never got the reaction they wanted because he would just say, "I'll see you tomorrow!"

David: Yeah.

Sariah: The next day, even though they said terrible things the day before, he would say, "Hi, friends!" He kind of just loved them out of it.

David: It never bothered him.

Sariah: It never bothered him.

David: You see how trusting he is. He has issues like a normal teenager. He definitely has his…

Sariah: …moments.

David: …his moments of parental discord where he challenges us on things, but at the end of the day, we are there to help him, and he usually goes along with what we are trying to do.

Gerald: That's super. Let me ask you a question about his impact on your immediate family as well as your extended family. David, do you want to take that one on?

David: Okay, that’s the hard question. As far as Spencer’s impact on our family, obviously we all know sign language, some of us better than others. Sariah is much better at it than I am, and Andrea is actually pretty good at it. We attend a deaf congregation for our church, so everything is done in ASL, which sort of changed who we interact with. We’ve gotten to know people in the deaf community, and we have many dear friends in that community. I don’t think that ever would have happened had we not had Spencer. He has helped us have a lot of fun.

Sariah: Yeah.

David: He is always the first one to laugh at something, and especially Joanna and Daniel look up to him as a big brother, someone they can trust. They might not think of it in those terms, but to them, he’s normal, he’s just Spencer. They don’t think that there is anything wrong with him. They just understand him to be the way he is and for them, that is normal. That really helps them have more understanding for other people they see who have special needs as well. They have an uncle who has special needs, too, and they aren’t nervous around him at all because it’s just normal for them to see somebody in a wheelchair. They are okay going up to him and asking him questions. Sometimes you see someone in a wheelchair and you wanna keep your distance, but they don’t do that. They are willing to go up and talk to him and even climb up on his wheelchair or even touch it, none of that is strange to any of them. I think that has probably been the biggest impact, that they can just see people for who they are and look beyond whatever else is happening around that person.

Gerald: Thank you. If I came to you and had just found out that I had a child who was diagnosed with CHARGE syndrome, what advice would you give me, Sariah?

Sariah: Start learning sign language right now would be my first thing. The second thing would be that there is a CHARGE syndrome website, and I would say to go there and talk to the specialists. They have specialists on the East Coast, and all they do is work with CHARGE syndrome kids. They have tons of experience and tons of knowledge, and they will coordinate with your doctors. When our son was really little, we lived in a fairly rural area, and it was far to go to specialists, and it was hard to go, so to have those kind of contacts was important. I know that the specialists associated with the CHARGE syndrome Foundation consult all over the world just on CHARGE, so they know what they are doing. The other thing would be to allow yourself time to grieve for the loss of the child you thought you were going to have, because when you don’t allow that process to happen, it can backfire real fast. You can end up suffering a lot more than you really needed to. Allow yourself to grieve, and whether that is writing a letter or having a ceremony or talking it out with a really good friend, it’s not what you expected and it’s going to be hard, but it’s going to be okay. I just wanted to add that there are going to be lots of doctors’ appointments, and there is going to be lots of therapy involved with children with CHARGE syndrome. Spencer is on more of the mild end, hence our very late diagnosis for him, but a lot of these children are diagnosed in utero or right after birth. There will be lots of machinery and lots of equipment that you will have the opportunity to use, you’ll become a nurse in your own right. I wish there was some sort of certificate we could give to our moms with kids who have severe medical issues because they become quickly just as qualified as a nurse. Take the opportunity to learn, and get in there and do these things for yourself and for your child. It will be an education and a trial by fire, but you will feel so much more accomplished and so much more achieved when you can do these things for your child yourself. Unlike a typical child, changing a diaper or giving them a bottle or nursing yours will be different, but with a little extra training, you can totally do it. There will be lots of appointments and lots of therapy and lots of surgeries, and eventually you’ll get used to it, and it will be your new normal. You will have a system for yourself and for your child, but in the beginning, it will be a little bit crazy as you learn these new things.

Gerald: David, do you have anything else you want to add?

David: I will just add that you can do this. Start with the CHARGE syndrome Foundation, but it is also important to find other families who have children with CHARGE to create that social support. It doesn’t necessarily have to be other families with just CHARGE, you can get involved with other families who have other disabilities. Locally, Sariah is involved with the United Angels.

Sariah: Yeah.

David: A group called United Angels offers a lot of support for a lot of families with children with any sort of special needs, so just get involved and stay involved with other people.

Sariah: There are lots of organizations in California like the Easter Seals.

David: Yeah.

Sariah: There were a bunch of other ones; I can't remember all of them.

Gerald: The point is to find a group.

David: Yes.

Sariah: Find a group.

Sariah: Finding someone online is great, but it's better if you can find someone in your local community who understands that going to the hospital on a regular basis is hard. This is something that I tell other families that I meet who are going through a new diagnosis, pack a bag and have a backpack by the door. For a long time, we had a backpack that just had fun things in it for Spencer, because we could end up at the hospital at a moment's notice, and it was just easier to have our own stuff, our own snacks and things I knew he could eat, things I knew he could tolerate, things I knew that he liked. Because vending machines, let's face it…

David: Or hospital food in general…

Sariah: Hospital food in general isn't always that great, so I took things that I knew he would enjoy. I always kept Sudoku and some crocheting stuff in the bag for myself, because a lot of times, your kid is under anesthesia, and you're waiting. There is just a lot of waiting, so just having those kind of conversations with other parents and gleaning from their experience helps. You don't have to reinvent the wheel. I have already walked down this road, come meet me here at the middle of the road instead of at the beginning of the road, and we'll walk the rest of the way together. You don't have to do it by yourself.

Gerald: That's great advice.

David: I was probably not the best at this, but going back to what Sariah was saying about the grieving, it's important that you allow yourself to feel whatever emotions you're going to feel about it and to work through those emotions.

Sariah: And it's okay.

David: Yeah.

Sariah: It's okay to be sad or mad or confused. That's okay, and that's really normal. Feel it.

David: Yeah, but as you do that, it's also important to remember to have fun with your children despite whatever horrible thing you're trying to deal with. It can still be fun, and it can be a joyous experience. If you look for the good in things, then you'll be able to look back at those moments with joy instead of fear.

Gerald: Great advice.

Sariah: As example from our life, Spencer was four months old and had a feeding tube and an apnea monitor, and we found adapters for our car so that we could run the pumps and things using our car battery, and we went for three days up the side of a mountain to a family reunion.

David: We went camping.

Sariah: We went camping with no plumbing, no running water to toilets and porta potties toilets, and he played in the dirt and had a grand ol' time. You can do it. You can take your kids and do normal things. Whatever it was that you planned to do with this child before you had a diagnosis, you can still do all of those things. It might take a little more effort like finding adapters, but once we found adapters, it wasn't so hard to do, it was just like going camping. It was fine, and that is kind of how we've done things with Spencer. We don't exclude anything, he does everything that we do, that we would do anyway. I don't think we've ever looked at a situation where we thought, "No, that is going to be too hard, because we have to take Spencer."

David: I don't think we have ever not done anything.

Sariah: Even, David's little brother, was in a wheelchair, and we used to live about five minutes away from them, so our families did a lot together when Spencer was young. I didn't think, "No, that is going to be too hard, let's not do that." We just thought, "Let's go and do," or, "Maybe we should make an accommodation for that."

David: We've taken wheelchairs where wheelchairs should never go.

Sariah: Evan has been lots of places, and same with Spencer. We just take our kids wherever we would go normally, whether we had a child with a different ability or not. We just treat them as normal as you can, and do whatever we had planned. In the early years, because Spencer had so much developmental delay, we didn't know if he'd ever go to college or live independently or drive a car. Right now, I can say that he is in college at UVU in his second term. He is taking concurrent enrollment classes, and he is doing pretty well when he remembers to turn in his homework, he is 17, so he forgets.

David: He is your typical normal kid in high school.

Sariah: He is taking concurrent enrollment, so he is taking college courses and getting high school and college credit at the same time, and that's pretty good for any typical 17-year-old. He does it with accommodations, he gets extended time for testing, and he has an interpreter with him at all times. He gets copies of the notes from other students and from the teacher so it's possible. You can make it work. It might take making a little bit of extra effort, but you can totally do it.

Gerald: That's great. You guys are awesome. Thank you for taking the time to tell me a little bit about your life with Spencer.

Sariah: Sure.