Solo Q&A Episode with Beth

Beth: [00:00:00] Hey guys, and welcome back to another episode of the Love and Language Podcast. I'm Beth and Christy is out this week. I think just that transition into this, summertime is always a little chaotic, so we've had a pretty hard time matching up our schedules. So you have just me today and I am going to be doing a little bit of a q and a session here.

Beth: I got some questions from people on Instagram, so going to go through some of those with you guys. So we are going to kick it off by chatting about whether or not I knew Cooper was going to be deaf when I was pregnant, or if he, We only found out after the fact. And for us, we found out after the fact.

Beth: We had no reason to think going into my pregnancy or having a baby that, he would be deaf. There was no reason to screen for anything. And honestly, it wouldn't have even shown up as it is because we still have not been able to pinpoint genetically his exact reasoning for his being deaf.

Beth: His clinical diagnosis is Wardenberg syndrome, but genetics have been a little more inconclusive. So we did not know. He [00:01:00] referred on his hearing test right away out of the hospital, and we got his official diagnosis when he was six weeks old. Honestly, I think I prefer that. I think it would've been harder to wrap my head around if I had known my entire pregnancy.

Beth: But then again, maybe it would've been time to really research and think and dive in and all of that without a newborn. There's really there's pros to both ways. But I wouldn't change anything about how it played out for us. Another question, so this kind of goes hand in hand.

Beth: Does anyone in your family or Brandon's have the condition that Cooper has? Like I said, Cooper's clinical diagnosis is Wardenberg syndrome and that it's a genetic condition. There's four different types. And there's six genes associated with it I believe. In Cooper's case, those came back inconclusive.

Beth: So there's probably another gene associated that they just haven't found yet because that does happen we were told in about 10% of Wardenberg cases. So we've had a hard time pinpointing where exactly that has come from. But Brandon does have Deaf relatives. His aunt, his [00:02:00] cousin and her kids are all Deaf.

Beth: However, they don't really have any indication of Wartenberg syndrome. It's at this point just seems a coincidence, a. Spontaneous mutation. I, that always sounds so funny to me. But that's what we've been told at this point. We don't know the likelihood of more kids that we choose to have

Beth: having Wardenberg syndrome, we were told to just plan for that 25 to 50%. It would not stop us from having more kids. We just aren't at that point in our life yet. Let's transition. I had a couple questions about surgery specifically. So how did Cooper react coming out of surgery and what was I worried about going into his surgery?

Beth: Cooper had his cochlear implant surgery when he was nine months old. It was June of 2020, so right in the midst of Covid and. It was a lot. I, we could only have one parent at the hospital, so I was there. I guess my biggest worry was that they would, find something that had been missed up to that point and that we wouldn't be able [00:03:00] to go through the surgery or that his implants wouldn't work for some reason.

Beth: Obviously that was not the case, but I think that's always a concern. I did feel like overall I was relatively calm. It's. It's an outpatient procedure. We went home the same day that he had the surgery and it took about five hours, I think, total for both sides. Coop had a hard time coming out of the anesthesia, which was a little bit of a shock.

Beth: Not necessarily a shock. I just had heard from so many parents that their kids bounced back after surgery so quickly, and he definitely took a little bit longer to come out of it. One of the biggest things that I found out after the fact that was, concerning in the moment was that nodes bleeds are pretty typical post-surgery.

Beth: It's obviously concerning when you see blood coming out of your child's face after a surgery, so I wish I had known that going in. I always tell that to parents who have questions about. What to expect or what did you not know that you wish you had known type of thing? I would say Coop took about, he was really back to himself about [00:04:00] two days later, and at that point it was just waiting for those incisions to heal.

Beth: They weighed about three to six weeks, typically before turning implants on to let those heal, to let the swelling go down and give that magnet site time to be optimal when it comes to turning them on. So the other thing that I wish I'd known was that sometimes, at least in our case, the stitches that are put into the incisions are dissolvable and they don't always dissolve.

Beth: So he had a couple spots that got pretty inflamed. Red, just irritated and I was just, Obviously super worried that it was infected or he was, body was like rejecting the implants and that was not the case. They just had to go in and actually take those stitches out. So overall, surgery, we couldn't have

Beth: Asked for a better team. We couldn't have asked for it to go better. Obviously I say obviously a lot, being mid covid made things a little bit different, but I feel very fortunate that we actually were able to, have his surgery considering it's an [00:05:00] elective surgery at the end of the day it went as well as we could have expected.

Beth: Another question, this is a good one that I haven't thought about. So it says, for standardized tests we can't have electronic devices. Does that apply to him? I would assume he can still have his implants on and his microphone to hear directions. He would still have to leave his phone outside the room obviously, so he wouldn't be able to like Bluetooth his implants to it.

Beth: I can't imagine that they would be able to say that he can't have his implants on in order to like, hear directions for that. And if that were the case, he would have me to deal with. So I guess we will cross that bridge when we get to it.

Beth: What is one blessing we've experienced on the journey? Just one. Gosh, I could go on and on about all of the silver linings, but I think the biggest thing that I am so grateful for is just the community that we've built and the people that we've met. Even Christy, like we wouldn't know each other if, our kids weren't deaf.

Beth: We would just be existing in our own worlds. And [00:06:00] it's really crazy when I think about how many people are such a presence in my life now that I didn't even know existed before Cooper. And to see all the good they're doing and the passion they have and the way that they're raising their little humans to be advocates for themselves and.

Beth: Change, the narration and the conversation around, being deaf, being bilingual, using hearing aids, using cochlear implants, using sign language. It's just a really awesome thing to be a part of. And obviously I never anticipated being here, but I am so glad that I do get to be part of it.

Beth: Somebody else said, my son's implant is being activated this week. Did you ever use caps to keep Cooper's CIs on? We did not. We used headbands from the very, very beginning for his hearing aids even. And so I think he was

just so used to having that on his head. I always say if anything, that's what the hearing aid trial provided for us was having him used to having something there more he didn't get any sound input out of his hearing aids.

Beth: [00:07:00] But I do think it contributed to him being very willing to keep his implants on. We love the actual, like cochlear brand, pediatric headbands. Those are the ones that we use all the time. They're thicker, they have spots so that the implants can't slide around and move. They keep them really locked in place, right above his ears.

Beth: And I will buy those over and over as long as we need. I do know that, people use caps and have a great amount of success with it. I know some people really like the snug fits, which just loop around the ear when they're a little bit older. We tried that did not go well. So we just, headbands have been what works for us, but I would say be willing to try all of those options.

Beth: Another question about his implants and water. So can he wear them in the rain? They are technically supposed to be water resistant. They are not waterproof. I don't love them coming in contact with water. I feel like we've had issues because of that. At points we, if it's raining heavily or he's in water, [00:08:00] we typically just take them off.

Beth: If he's in, a pool and swimming for a prolonged period or. Playing outside in a sprinkler, we put his aqua kit on and that is basically waterproof sleeves that go over his implants and microphone, and then a waterproof coil that replaces the coil that he wears day to day. The reason we don't do that super often is just because it's a lot of on and off.

Beth: And they're really snug. Then his headband is wet, and so it's just a whole thing. A couple brands do have waterproof processors, but I just didn't see us using them enough. Being in Minnesota and having, winter, like six months of the year that it didn't seem worth it to get that as our backup option.

Beth: So we just have two sets of his cochlear NM seven s. They're identical in case something happens to one. We put his aqua kit on when we know that he'll be in water for a long time and he seems to hear really well with that as well.

Beth: Last question for now is how did your family and friends react when you first found out that Cooper was deaf? I think it was a combination of things. [00:09:00] I feel like it was a little bit different for us because the people close to us, our family, everybody knew going into that six week, a b r, like his advanced test.

Beth: We, we knew, we had a good feeling that it was going to be the news we got, which was that he was profoundly deaf. We had Wardenberg syndrome already on our radar at that point and knew that hearing loss and being deaf went hand in hand with it. It really wasn't a shock. Personally, I think I was holding out a little bit of hope that, he had like moderate hearing loss or, something like progressive hearing loss because that just felt better to me than being deaf because that scared me at that point.

Beth: And in retrospect, obviously it was actually a good thing that he had the level of hearing loss that he did because it made him a cochlear implant candidate much sooner than he otherwise would've been. There wasn't really a lot of that in between and waiting phase. As far as our family, my, we went directly to my parents after we got the results from that test, and I just cried and cried.

Beth: I cried a lot. I was just scared. It was a lot to process, even though I knew that it [00:10:00] was coming. Having that definitive answer was scary and my family is great about just letting me feel what I feel, but also reminding me of the. Things that we've, the things that I've felt that way about in the past and have had to pull myself up and overcome.

Beth: So there it's a great mixture of, empathy and compassion, but also logic and reasoning and support. And the same could be said for Brandon's family. It's different obviously we have very different families, different backgrounds. Brandon's mom's sister is Deaf and has a couple deaf relatives on that side of the family,

Beth: so it was familiar in that sense. Our friends were great. People knew people who had a deaf child or a child with hearing loss and made those connections for us and were supportive. And the most meaningful thing to me was when people took the time to learn some sign language because they knew that between now or now being, when we found out and his [00:11:00] surgery, he was not going to be able to hear.

Beth: Or people that even take the time to learn signs now. It just means a lot. That people go out of their way to be good like that. We didn't have any issues when it came to the reactions of the people around us. We had support and confidence in our abilities and parenting, and I think at the end of the day, that makes a huge difference.

Beth: It's important to have that, but I also want to state that it's important to have connections with people who are going through or went through what

you're going through because your family and friends can be beyond supportive and it's necessary and it's meaningful, but it also makes a huge difference to just talk to people who get it, who have been there, who have felt the feelings that you're feeling and who have been scared for their child and their future, and what that looks like and who have put in the effort to give them every

Beth: possible positive outcome that they can [00:12:00] and come out the other side. And I think that at the beginning was what gave me so much hope, was just seeing other parents, specifically for me, parents on this journey, raising d/Deaf children and realizing that they were just normal kids and that their lives were the same.

Beth: That goes back to, being a part of this community and feeling so grateful for that. I never thought I would say this, a few years ago, but at the end of the day, I wouldn't change it.

Beth: All right. That wraps us up for this week. Hopefully those questions gave you guys a little bit of insight. If this is a journey that you're on Christy and I will be back next week. We are going to dive into the cochlear implant surgery process a little bit, which I know I get a lot of questions about.

Beth: I'm sure Christy does as well, it will be really helpful for people who are heading into that part of this journey. So until then, remember, as long as you're giving your child love and language, you are doing a great job.