Welcome to raising a child with hearing loss with host Gretchen Fors. Gretchen is a mother of five children, three of whom are hard of hearing. Listen as adults, teens, parents, and providers share their own personal journey with hearing loss Plus hear the stories of moms who have walked this journey alongside their child. This podcast is intended for families to share their own personal journeys without judgment. Please respect and honor each family's choices. All information presented is educational and should not be Misconstrued as personal medical advice.

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Hi!. Brittany so excited to have you on today and really excited for you to share [00:01:00] your story. So I'm just going to let you take it away and introduce yourself and tell us a little bit

about your family.

Brittany: Thank you so much, Gretchen, I'm grateful for this opportunity to share our story.

My name is Brittany and our daughter, Pearl. She is almost 18 months. She is deaf. She's hard of hearing.

Gretchen: How did she get diagnosed? How did you find out that she

had hearing loss?

Brittany: Right after she was born, they did the hearing screens in the hospital, which typically you don't think much about, I have two older children, so it's always thank you for the screen. That's fine. They came back in after the hearing screen and said, she didn't pass. But that's pretty normal. A lot of newborns don't pass because they have fluid in their ears or it's just too early. So don't be worried about anything, but she didn't pass so we will test her tomorrow.

So I said, okay, sounds fine. And then, the next day. They did the hearing screen again and she failed again. So again, they came in, she failed again, but don't worry, same issues, it's only a day later. So what we'll have you do is come in a week [00:02:00] and we'll test again. And so at this point I was like, ah, that's interesting, but I wasn't too concerned, just based on how they were handling it.

Gretchen: There was no family history of hearing loss, it's not like you've had any family history and no complications with the pregnancy and she didn't end up in the NICU. She didn't have any antibiotics. There was nothing. That was a red flag

that way.

No. Yeah. Yeah, no, no issues there that we were aware of. Then, I also, at this point I had a friend who's an audiologist, I reached out to her and I said, what do you know about this? Like they say, Common for newborns not to pass. She reassured me too, it could be something, but also it could not be something and you'll learn more as you go.

And just comforted me. I was just like, I needed a little comfort for my mama heart, I just have a new baby and so many emotions anyway. So we went in a week later and she failed the hearing screening again. And we are

like, Kay, what does this mean? And they said, again, it could still be just she's new and she has fluid in her ears or whatever's going [00:03:00] on, but because she's failed again, we want to bring you in to do an ABR test, to confirm, if this is indeed a true hearing loss or not.

So ABR is auditory brain stem response.

Brittany: We went in a few weeks later to do the ABR test butbut before. We went in for that test. I think this was something that really helped us along the way.

My husband and I, after the first failed screenings, we just sat down and we basically just had a conversation like about the reality of Pearl having hearing loss. What would that be like? And I think there was some pain around it.. And those were coming from thoughts about all that she's going to miss out on.

And I think something that was hard for me was like, everyone during pregnancy says, your baby can hear you and you're connecting to your baby and just keep talking to your baby. They can hear you. And I was having all these thoughts, like what if she hasn't heard this whole time? And what if she never will you know.[00:04:00]

So thoughts like that were causing a lot of sadness, for me. But then as we talked through the, during that conversation, as we just, talk through everything, how we were feeling and all of it, we just had this thought, like we've always had hearing and we assume that life is best with hearing, but what if we're wrong about that?

What if, What if there's some really great things about not being able to hear that we're not aware of. And then we just thought regardless whether or not she has hearing, we just felt so strongly that she will have a beautiful life to such a beautiful life. And we felt that so immensely and it was like, Our grief suddenly just became peace.

And in that conversation, and I was so grateful for that. I was so grateful that we took some time to mentally prepare ourselves. And I just felt really blessed through it really that we could feel this peace. And I was back and forth, I would say. I think she has hearing loss.

What's this going to be like, and [00:05:00] then I'd be like, no. I really don't think it'd be really rare for her to, why would you have hearing loss? It's so random. And I just went back and forth, all throughout the next few weeks until we waited to have that test. So then I did go in for the ABR test and it was in COVID land.

You

Gretchen: go in with your husband or were you by yourself? I

Brittany: was by myself. Yeah. Yeah. COVID was crazy. Had to labor with a mask on and all that, which is fine, but the whole process anyway was just like, the dynamics have been interesting. So I went in by myself for the ABR test and, It's, it's quite a long test, especially when you, as a mom are holding the baby and trying to keep them comfortable and keep them asleep.

And it takes longer if they wake up. So it's just a lot of time to just sit there and think you can't really do much because you're holding your baby to stare at your baby thinking like, what's this going to be? What are we going to find out today? And during it, I would try to like, watch the audiologist and get a feel for.

What's going on, you can't tell anything. We [00:06:00] waited through the test and then at the end, she did confirm that Pearl did have hearing loss. And, I think all those feelings again came rushing back, like sadness and confusion and. Just overwhelmed and shock, mostly shock.

Like

what?

Oh, wow. What does this mean? But then, I felt the audiologist handled it very well. She was very kind and she's take all the time you need, it's totally fine to cry. It's totally. Everything's fine. And, she was very supportive, which I was grateful for. And then after feeling all of that, I just also just felt this really sense of peace and that we would be okay and we would get through, and this would be just such a journey for us, and she gave me a little book that was like, a children's book about hearing loss. And I think I was like, I'll use this to help my, older children process it. They're still young too. But, so that was like how we found out about it. And, as soon as I left the hospital, I called my [00:07:00] husband and I just cried, but it wasn't, I didn't feel, like a lot of desperation or why me or any of that.

It was just like processing it. And so many feelings, as we drove away and thought, yeah, what real, what will this look like? I just also felt so much gratitude for my daughter at that time. And. I just, most of all, I was like, I just want her to know that I'm here.

I love her. And no matter what, like we'll get through it. So sorry to get emotional.

Gretchen: Pearl's lucky to have a mom who loves her so much. Thank you. What did they tell you? The next step was like, once you, obviously you went home, you talked to your husband, you process what the, some of these feelings and emotions.

But after that, what was the next step for pearls?

Brittany: Yeah. So they told us that they would put us in touch with a [00:08:00] different, long-term pediatric audiologists. So they set us up with her.

They said, she'll contact you in a few days and you can set up your appointment to discuss like what you want to do from here. And they also set us up with, like the early intervention services to get us involved there. And I felt like they did a very thorough job there of it's a lot to take in, but it's here's this information in a few days, someone will call you and help you with the next step.

And I appreciated that because I think a lot of times, It's put in the parent's hands to go and figure things out, which is fine. But sometimes when you're trying to figure out what who's next and what appointment am I supposed to schedule? It was so nice to have a team of people who suddenly we were on their radar and they reached out to us to say, we're here for you.

We're going to get you scheduled. And so that process went well. And then when we met with our audiologists, We really liked her and she'd come highly recommended.[00:09:00] She basically told us that the best scenario, so Pearl was diagnosed with bilateral sensory neural hearing loss. And she's moderately severe.

So they said our recommendation at this point is to have hearing aids. Because that will allow her to have access to sound and be stimulated as much as possible. As we navigate whether or not you'll want to do a cochlear implant in the future, because she's right on the edge she's moderately severe.

And so it's like at this point, we don't know if hearing aids are giving her the full range of sounds.. We don't know if she's getting those higher frequency sounds and that will only be able to tell that as she gets older and can verbally Q us. Yeah, I can do that. No, I can't. So they're like, the best thing we can do is just to give her as much sound as possible and stimulate as much as we can to allow that to happen.

We reviewed the information [00:10:00] and thought what do we want to do? What are our options? And we felt strongly, the hearing-aids were a good way to go. So two months after she was born, she got hearing aids and she's had them since then.

Gretchen: It's hard to keep hearing it's on a two month old, and now she's 18 months old, so she's had them for 16 months. I'm sure people would love to know, some of those stories . And also crazy and also super stressful things that happen trying to keep a hearing aid on a baby and an infant and a toddler.

Brittany: Yes. Yeah, for sure.

That's that has been one of our biggest challenges is keeping hearing aids in. So she's gone through phases sometimes she'll just not touch them at all for a few weeks. And then sometimes it's like incessant. The minute we put it in, she pulls it out. Which. mothers and fathers who've dealt with this, know the pain of it.

I heard a few different suggestions. We got one of those caps that you put over and go under she's smart. And she pulls the whole thing off, or [00:11:00] people talked about tape, you can tape the hearing aid on. So we tried a few different things. But I was also like, In the end though, if she can get the hearing aid out, she can get whatever's holding it out or off.

So our most stressful experiences with that has been when she's been in the car and she's taking them off and drop them. And the one time that I really thought it was gone, for sure. We had just driven about an hour to a family wedding and driven home and we couldn't find it anywhere.

And I was like, it's somewhere in the parking lot at that wedding. But we had searched that the parking lot because we had noticed it was gone. I was trying to enjoy the family event. I felt so bad. I saw one of my cousins I haven't seen for years. And I was just like, I'm so sorry. I just lost a hearing aid.

And I don't know where it

is. And

it's so good to see you. I'm little, a little stressed. I just felt bad that it was like taking over the event, we were able to enjoy the event, but we searched and searched for this hearing aid. We couldn't find it anywhere. We came home, we searched, we [00:12:00] searched and it was like, this thing is lost.

We are praying for it. Where can we find this hearing aid? My sweet nephew was in town and . He said a prayer about it. Just so sweet. And then, after about an hour of searching the car, we found it like wedged between the seatbelt and the.

The buckle and the seat, like way far down,

how did he even get there? But we found it and we were so relieved. And ever since that day, I'm so committed that she never wears I'm in the car. Even if we're in the car for two minutes, I just I've had a few experiences. And that one was the worst that the car is just the worst place for her to have them.

So at this age, at this point, We just take them out every time we're in the car and we've had some people say it might even be the feedback in the car. Maybe she just doesn't like it. It could be a thousand reasons. Right now, she's in a good phase. She's been in a pretty good phase for , two months or so.

My audiologist keeps saying, just wait until she's two and she'll get back at them again. So I don't know [00:13:00] what your experience has been with that, but it's a journey for sure. To try and keep thosein.

Gretchen: Yeah, I think that's great. You shared that because I think most moms will have similar stories, right?

And just like Pearl, my child who had the hearing is the youngest, also two older siblings. So when you have two older kids, you spend a lot of time in the car too. Oh, pulling the hearing aids out, not swolling the molds, finding the little pieces everywhere.

To be honest, I had did the same thing. Like she just can't wear them in the car I think that is a very common problem.

Brittany: Yeah. And we've found on, down her onesy. At one time we lost it. We couldn't find it anywhere. We'd search in the whole time it was on her. It was just like inside of her clothes next to her diaper. We're like, oh, my

Gretchen: what would you say the biggest challenge has been keeping the hearing-aids on or what do you think? Really? The

biggest challenge has been

Brittany: beyond keeping the hearing aids and which is, for sure been a challenge. I would say emotionally, the hardest thing for me has been days that I feel like I haven't done enough, like wondering, oh man, like getting [00:14:00] to the end of the day and thinking I didn't read to her today.

Like I should have, or I didn't like loop her into my conversations or I wasn't aware of her. Like I should have been and just having feelings. Like I hope I'm doing enough. And I think like with the older two, I'm used to how they were as babies and treating them as if they can hear cause they can hear.

And so to try and sometimes remember like you have to be extra aware and talk more and include them in conversations and self-talk so they see what you're doing and can identify what you're doing. I think those are the hardest, emotionally challenging moments are just when I think am I doing enough?

Am I aware of her enough and do I need to read more books to her today? I had someone tell me that they had a therapist that was telling them to read 20 books a day. [00:15:00] And she was like, I know that's a lot, but I think it helped us anyway. And she was annoyed pressured me, but. Oh man, I'll shoot for 10 a day and see where we get, which for awhile it was okay.

But then you get burning out and then, you have to find the balance of including them and reading a lot and doing things you can, but also realizing you have to move forward in your day to day activities and not feel stuck.

Gretchen: So she's wearing hearing aids currently.

And what services are you getting? I know that you had said that they looped you into early intervention and things like that, do take her to therapy, do people still come to your house?

Brittany: . We don't take her to therapy yet. Any speech therapy. We have early intervention services and it's called PIP here.

I don't know if it's the same where you are. It's the parent infant program. So twice a month, we have a PIP advisor come to our house and they check in, see how we're doing offer support, and then we'll offer [00:16:00] like techniques to include them and, be aware of their speech and, tactics you can use to help with all of that.

So that's been like a really great thing to have also through PIP. We've had the deaf mentor program, which, so we're doing LSL and ASL and, I fully support anyone's decision to , make any choice regarding language. And for us, we felt like the combination is a good fit for us. And through that, we have a deaf mentor coming once a week, to help us with ASL. We've just loved that opportunity. It's been really great. From family support side, we've had such great services. I think early intervention has done a great job. PIP has a lot of events. They hold online and in person now more with COVID, restrictions.

Decreasing a bit, but, it's been great. I felt the community a lot from that, which has been super helpful. And also back to the medical side of [00:17:00] support, we were immediately set up with an audiologist, was an ENT, was a geneticist, and they'd been our teams since day one. And that's been also amazingly supportive.

To just have this team who's working with us. And when we go to an appointment, the others check on the team and how's it doing and how are we progressing? And that's been really great. So we felt so much care and so much support, and I've been very grateful for.

At 18 months. Does she have any language yet. Is she saying any words?

I know it's still a little bit early, but does she have any words about how many words, about how many signs does she have?

Do you know?

That's a really good question. Words I need to sit down and count her words. Probably. Five to 10 words, let's use like actually using, but she has almost 50 signs.

Gretchen: Wow. That's great.

Brittany: She's making lots of connections and it's been fun to see where she's using signs and words [00:18:00] together now to. I think she's doing well. She's making improvements and it's just fun to see, I don't, I wish I had the statistics of how many times a word has to be

a child has to be exposed to a word it's a really big number before they can first understand it. And then they have to be exposed to it so much more, to be able to speak. Or sign it. It's fun to watch that process, I think as parents, it's sometimes exhausting to be so repetitive.

I have told them this word 3000 times, they ever learned this word, and then one day they'll say it or they'll sign it. And it's just so rewarding. And you're like, they are learning from such a young age. They pick up so much. Never underestimate. Your efforts of, whatever you're doing.

I just think we can really help them by doing small things each day.

Gretchen: Yeah, I love that. And how do you think that this has changed your family dynamic? Because she does have two older [00:19:00] siblings and are they learning sign along with her and with the deaf mentor?

Brittany: Our older children and also learning sign, and that's its own adventure to, to try and figure out also because, it's new for them and it's confusing for them when we start learning sign language and they're like, why aren't they talking?

I'm like, no, in this, lanugage we don't use our voice. We use our hands, so it's been a journey. Just first, help them understand what ASL even is and then figure out how to best teach them. But I think through the deaf mentor program, With someone in our home every week that will help. I do videos every day that sometimes they join me for sometimes they don't.

We'll see how they do as they get bigger. But, in general, like Peral's diagnosis has greatly effected our family story. My day to day looks so incredibly different. Today. Then it would, if she did not have hearing loss, because a good portion of my time is spent, connecting with the PIP community arranging appointments, meeting with [00:20:00] people, learning sign language, like any spare time.

I'm always thinking oh, could I get another lesson in? Or, oh, what can I do with signing now? Or, oh, the PIP advisor's covering, we can work on these things. My day to day has just completely changed. And, back to my older children, I love to see the impact that all of this has on them because, beyond the language part, I just love them, having access and awareness of other people and their needs.

I think it's such a beautiful thing we've gone to several events with the Deaf community and I just love. Their ability to interact with them. And I just think it's increased their social awareness a lot. And I love when I hear them talking to their teachers or their friends about their sister and she's deaf.

And what those funny things in your ears are. Because so many of their friends will come and be like, what's that, so openly, which I love the opportunity to go. This is a hearing aid and this is what it does. And it's [00:21:00] just been a blessing for them. And, for all of us to just be aware of others.

I think the biggest, blessing of that and. Also just like how it's changed us so much is the relationships we've made and we've created, we've really been doing this a relatively short time, but we have made some amazing connections and created amazing relationships with people that will last forever and have just been so incredible.

It's like truly sacred to me. The journey has been really sacred.

Gretchen: Britney, you're just such a beautiful soul. And I really appreciate you sharing that because I do think that sometimes when first we get the diagnosis, we feel like it's a loss, we've lost something. And the reality is that we actually gained something.

And I agree, like I have gained so many friends and connections and community I would have never had, had I not been on this journey. And I'm grateful for all those people in my life. And it has [00:22:00] been more, not less. For sure. So I really appreciate your amazing perspective on that. And I hope that perspective brings hope to those that are struggling with wherever they are on their journey and that there is something good on the other side.

So I really appreciated that. And I also am really impressed with how well all of the services have worked for you, the system is working where you're at, where she got diagnosed early, the newborn hearing screening. The referral process was correct. And she got to where you needed to be, and that you feel like your team is so supportive and that people put their arms around you and really helped you move forward in your journey.

Brittany: Fairly fortunate that way, because I know it's not always that way, but we have, yeah. We felt a great sense of community and support. I'm very grateful.

Gretchen: Thank you so much for joining me today and thank you so much for sharing your heart with others and sharing your journey with us. So thank you so much.

Brittany: Thank you so much, Gretchen.

Gretchen: [00:23:00] Thank you so much for joining us for today's episode of the hearing mamas tribe podcast. I'm so appreciative for those who are willing to share their stories. And I hope as we share and listen to these stories that our hearts can be uplifted and we can find joy in this journey together. I welcome you into our tribe.

If you're a parent, a mom, a dad, or a professional who serves these children. And we'd love to share their story. Please check out the show notes for how to get in touch. Please like subscribe, share this with your

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