

Catching YOUR Memories

THE PODCAST

WITH DIANE ATWOOD

How a child born deaf unlocked his parent's hidden potential

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[00:00:00] Everybody has a story, an experience, or a memory to share. If only someone would ask. That's where I come in. I'm Diane Atwood and you are listening to the *Catching Your Memories* podcast. On Christmas Day, 2019, Claire Jeffers and Ben Lake welcomed their first child into the world.

Seven weeks later, on Valentine's Day, they learned that their son was deaf. Just as they were beginning to access the many valuable resources available in their home state of Maine, COVID hit. That meant, for the most part, that any connections they made had to be online, not in person. Still, they managed, more than managed those great upheavals in their lives. A pandemic and having a deaf child. This is their story, told by Claire.

Diane Atwood: Welcome to the *Catching Your Memories* podcast, Claire. I'm so excited to be talking with you today. You have an amazing story to share.

Claire Jeffers: Thank you. Thank you so much for having me.

Diane Atwood: So, we're gonna be talking not just about your son, your remarkable son, but his remarkable parents. That's what strikes me as I have listened to and read about your story because you could have taken lots of different paths, even in just this short time, but let's start, I think I'll start with your pregnancy. Absolutely routine kind of a pregnancy, not that you've been through them before.

Claire Jeffers: As far as I understood, I had a pretty typical pregnancy with no complications, so I was very lucky and, for the most part, felt pretty good most of the time.

Diane Atwood: And then birth, nothing out of the ordinary?

Claire Jeffers: Also nothing out of the ordinary, for, what I had read and learned about, labor. It ended up being a pretty typical first-time labor and delivery. We also had [00:02:00] no complications there. Again, extremely lucky and very grateful for that. While it was, you on the longer side, 24 hours of labor, it was also uncomplicated and ended up being a really positive experience, yeah.

Diane Atwood: The hearing test. I had my children 30-plus years ago. I don't recall a hearing test being done. Is that something new that they do or did I just miss that?

Claire Jeffers: So, I can't say for sure in terms of your kids, but I know that it became state mandated to have the newborn hearing screening. It definitely was not mandated when you had your kids 30 years ago. Whether or not they had a screening when they were born in the hospital, they may have. It just wasn't necessarily required.

Diane Atwood: And how do you screen a newborn?

Claire Jeffers: So, it's a bunch of little wires and little magnets and little things that they tape to the baby's head. I actually wasn't present for the newborn hearing screening for my son. My husband accompanied our son to the room where they do a couple of tests after the baby's born. I assume I was somewhere, hopefully sleeping or resting, but about a week later, we ended up going back to the same hospital to redo the screening because our son did in fact, refer, which, some people might say fail, but we call it referring on the new newborn hearing screening. Because then that indicates that there needs to be additional testing. Your initial pediatrician visit, the pediatrician will look at all these initial tests that the newborn had in the hospital. And course, anything is flagged for them, that's when they jump into action.

Diane Atwood: When your son had that first screening in the hospital, it was flagged immediately likely. But were you told about that when you were in the hospital? Was it explained to you?

Claire Jeffers: We were definitely told, and then again, my husband was present immediately upon them finishing this hearing screening. The nurse informed my husband that they weren't getting a read on this screening. So [00:04:00] for whatever reason, and the nurse doesn't have any more information than that. Unfortunately, at this point of contact, there is not a lot of information. So, sometimes it can be pretty surprising news, but there just isn't enough information to know to do or what it means. A lot of the nurses end up saying, there's likely fluid in the ear, you know, the fluid will make its way out and I'm sure the next screening, the baby will pass the screen. That's often what parents in our position are told by nurses and sometimes they're right. Sometimes it is fluid in the ear, just from passing through the birth canal, there's fluid and it gets clogged up in the ear and it makes it hard for the screening to work. That wasn't our situation. That wasn't the case for us. So, at that time, we definitely were kind of a little puzzled, a little surprised, but my personal reaction to that, I just didn't really have any major concerns. I thought, oh, we'll follow up on another screening. It wasn't top of mind for me, you know, the top of mind for me was really obviously that I had just had this baby and I was overwhelmed and overjoyed and all the different feelings that come with that. I was also learning how to breastfeed and priority number one was making sure that he was getting enough milk, which while we were in the hospital, he actually wasn't getting what they would consider enough milk. So I was pumping in the hospital and making sure that he was eating at regular intervals more frequently than what I think he would have normally. So, I was very preoccupied with the basics. I just wanted to enjoy my newborn and make sure that he was taken care of, learning how to swaddle him, learning how to diaper change a newborn. so this little kind of flag was something in the back of my mind. I didn't really think about it and I thought, okay, well, in his one-week follow-up appointment with his pediatrician we'll touch base then.

Diane Atwood: You had a visit with a pediatrician then one week after he was born?

Claire Jeffers: It might have even been a few days, maybe three to five [00:06:00] days after the birth we went to see the pediatrician for kind of your standard follow-up appointment, and yeah, this did come up. That's where we started to learn a couple of different things. The pediatrician gave us a percentage, and I don't have the exact numbers in front of me, but I remember something along the lines of only about 10 to 15% of newborns refer on their newborn hearing screening. Again, I don't have that exact number, but it was not a lot, And that was the first time that I thought, okay, this is unusual. And in the same appointment, he said here's what we're gonna do. We're gonna get a follow-up audiology appointment for him and we'll go from there and we'll just

take this one step at a time, and as we learn new information, we'll talk it through.

And so, again, even at five or seven days old and me being five to seven days postpartum, I was really still adjusting to being a mom, adjusting to breastfeeding, adjusting to very little sleep. So even this new information wasn't that concerning to me. I just thought, okay, we'll do what we need to do and follow the steps. And the more we know, when we know it, is what will happen.

Diane Atwood: You didn't have to go looking for an audiologist at this point, right? It was all, all set up.

Claire Jeffers: I wouldn't say it was all set up. I would say we were definitely referred to a couple of different choices. So you're given a couple of different audiologists in the area where we live. And, basically, we were told to go ahead and give them a call to set up an appointment. We were in charge of scheduling it. I think the first available appointment that we were given was not until April 2020. So remember this is probably the first few days of January 2020 that we're told and my husband who was actually making these appointments, his first thought was that seems way too far away. So we called another audiologist's office and I think we were given another date. I [00:08:00] think we were also put on a waiting list. So anyway, long story short, we were finally able to get an appointment on Valentine's Day 2020, which was just shy of about two months from when he was born.

Diane Atwood: I'm feeling anxious just listening to this, you know because even though you're preoccupied with just trying to figure out how to be a mom and your body hasn't healed yet from giving birth, you've got this little thing that's hanging over your head and it's your baby. And I would wanna know tomorrow, I would wanna know today what's going on. So did that add some tension?

Claire Jeffers: I know it probably sounds really strange to say this, but whether it was some kind of self-preservation kind of, I needed to focus solely on the task at hand and not really worry about anything else. I mean, also these were the early days of, we were kind of starting to hear about Covid from overseas and there were certainly news stories and people were starting to talk about it a little bit. And I also remember thinking, this is gonna be something that just passes by. I really felt like I was kind of cocooning myself and my baby and just really not allowing a lot of other outside stress or challenges to come in. , but on the flip side, my husband definitely, I think, experienced what you described. He definitely wanted to know more information, immediately. And I think he

was maybe a little bit more concerned. and he might have even been holding back a little bit at the time just knowing that I needed to focus on, I was breastfeeding like 10 hours of daytime hours, and that's not even including, you know, nighttime.

Um, my son happened to just nurse for really long intervals, so I didn't have a lot of respite between breastfeeding sessions. If anyone is familiar with breastfeeding, which I wasn't at all before I became a mom, no one tells you what it's actually gonna be like. But he would take 45 [00:10:00] minutes to an hour each feeding and he needed to feed every two hours. So, it's basically around the clock, other than a couple two-hour breaks. I, again, really felt like I didn't even have the brain space or energy to focus on anything else, much less eat or shower. All the cliches you hear about early motherhood they're all kind of true.

Diane Atwood: Well, you made it to that appointment on Valentine's Day and they must have done extensive testing at the audiologist.

Claire Jeffers: Yeah, so we were told that it would be about a three-hour appointment, and sure enough, it was. It was almost exactly three hours, and that in order to get the best testing results or the most reliable results, if possible, he would need to be sleeping that whole time. Well, newborns don't really have a reliable sleeping schedule. So the best way, at least we could figure out, and I know other people that I've talked to have figured out is if the baby is a breastfeeding baby, you nurse them. You nurse them the whole time. and again, the baby's not on a schedule at that point maybe a little bit, but, essentially the best way to get them to be still and sleep or at least relax is to nurse. So I do remember nursing almost that entire appointment. We were in a very small soundproof booth, my husband and I and the audiologist, and he was hooked up with a bunch of wires and things on his head. It looked similar to the newborn hearing screening, but a little bit more complicated. There were lots more kind of more complicated computers and machines and ultimately it was just a very quiet room that we sat in for three hours and drank water and had a couple snacks and just waited until the audiologist was done. I also wanna mention too that In the weeks leading up to this, we were contacted by some really important and extremely helpful, both government [00:12:00] and state-funded agencies that ultimately became a huge part of our services for the next three years. This was a combination of child development services and then who they contract with, which is the Maine Educational Center for the Deaf and Hard of Hearing, Governor Baxter School for the Deaf. I'll probably refer to that as M E C D H H G B S D, and another program which is, A Guide By Your Side, which basically is a group of parent volunteers who have deaf or hard of hearing children who

are available to support parents like us at new appointments or really anything. We were actually given the opportunity to have a parent guide come to that first appointment and I remember having that phone call and being asked, do you want someone to come with you? And I thought, okay why not? This seems like a nice service. Might as well prepare for anything here and, and have support if we can. So sure enough, when we got to the appointment, the parent guide was there. One of her daughters is deaf and she was there just to kind of be a presence and be a support. She sat in a room outside of the soundproof booth for the entire three hours which is pretty remarkable. And, at one point towards the end of the appointment, there was a pretty clear indication that the audiologist wasn't really getting much information. I had never been in one of those appointments myself, but I could kind of assume that we might have maybe received some feedback from the audiologist, like, oh, okay, he heard that, or I wasn't really sure what we were gonna get, but, basically, there wasn't a conversation with the audiologist throughout the appointment. She was very focused on the task at hand, and I assumed and trusted that she was trying to get the best results as possible, or the most accurate I should say. So we were just kind of sitting there and it wasn't until the end of that three-hour appointment that I remember looking through the window to my [00:14:00] right, over to the parent guide who was in that other room and making eye contact with her, and seeing her face. And it wasn't that it was a sad face, it was kind of just this face of recognition of like, yeah, something's going on here. And this was even before the audiologist said anything to us. And, I had this feeling of like, wow, something's going on. And I think that was maybe the first time that I thought, okay, this is more than just fluid in the ear, or this is more than just kind of like a fluke, right? And sure enough, the audiologist turned to us and said we are getting severe levels of hearing tests, you know, I don't know exactly the terms she used, but I was also learning all of this in the moment. So the fact that there's mild-moderate, moderate to severe, severe, profound levels of hearing difference. I didn't know that those were the names of the different hearing levels. And so I was kind of catching up in the moment and she said we are getting readings at the severe level. And I think one of my first questions was can he hear us? Does that mean he can hear me? And she said, no, he can't hear your voice. And I think that's probably the moment that I started to go into a little bit of shock. It was kind of, you know, in the movies when everything else around you just goes completely silent and you're just kind of spinning a little bit. I'm not exactly sure what she said after that. I know that she gave us some information. There were some pamphlets that she handed us and I stood up and it was, it was clear that the appointment was over. It was kind of like, we're done here, like the testing's over. And we were told that we needed to come back in a few weeks for follow-up testing to confirm, of course. And I was holding my son and I had tears coming out of my eyes and I didn't really know what to do. I was kind of frozen. And one thing I really like to emphasize, as

I've [00:16:00] looked back at this moment, is that this wasn't a sadness that I was experiencing. There was certainly some aspect of grief, kind of this like, oh, this is a different experience than what. I thought I was having that, kind of grieving that a little bit. But, I really felt very scared. It was almost like a fear response. Like, I didn't know if I was capable of being the right mom basically for my son. And I wouldn't have been able to articulate any of that in that moment, or even in the days or weeks after that. It took me a while to understand what it was that I was feeling that day. Because by that time, we had an almost two-month-old. We had spent every waking moment with him since he was born, me especially, we had bonded, I was totally in love with my baby. I thought he was the most beautiful, perfect baby in the world, of course, which I still believe is true. So it wasn't that I was sad for him or anything. It was that this whole time I thought, okay, well I'm his mom. I can give him what he needs. I can do this, I am doing this. And then this news kind of felt like, I actually don't know if I can do this. And that felt very overwhelming because there's no one else for him. It is just me and my husband. And so that feeling of almost inadequacy was pretty overwhelming for me. You know, just the thought of everything that I knew that I would want to be able to provide for him and do for him. I was at such a low energy level, I was so sleep deprived and so exhausted already and had already gone through this steep learning curve of the newborn stage that it felt like I had climbed a mountain for two months and someone said, oh, so you're really tired and you're really hungry and you're just utterly exhausted, but I'm just gonna place you back down at that mountain again, and you need to do that again on zero fuel. That's kind of what it felt like, and that's kind of where the [00:18:00] feeling of impossible came in for me. It was, of course, a day I'll never forget. And I remember walking out of this soundproof booth, and I'm normally someone who's pretty decent at knowing where I am in terms of, you know which way to turn. And I'm pretty good at directions or at least having an instinct about things. And for the first time in my life, I literally could not remember which way to turn outside of this room. It was as if I had walked through a vortex and when I came out it was like a completely different world. And, my husband had to be like, we have to go this way. And again, it's just, all of this, I know it sounds kind of cliché and kind of, but you watch the movies of characters do these types of things and you're like, oh, they're being over dramatic. And I really was experiencing these things for the first time, and as you know, the day moves on. We had to go get lunch, we had to go home. The baby had to feed again. You know, like, the day just kind of moves on. We had to keep going. And there was definitely this feeling of overwhelm that day. We were like wow, okay, this is big. This is new. We have a lot of work to do. And that's kind of how the day ended.

Diane Atwood: So, it was helpful perhaps that the other parent was there.

Claire Jeffers: I think it was a nice way for someone to just kind of be there and witness. And, you know, there's really not much in those moments that can be said other than thank you for being here and we will be in touch. And I do remember I ended up texting her a few times over the course of the next couple weeks with random questions that would come to mind. Again, the overwhelm and, and the shock and reassuring us that I know it's a lot right now, but everything's gonna be okay and you guys can do this. She's still someone that I see at events and different organizational things.

Diane Atwood: Before you even had it confirmed that your son was deaf. Mm-hmm. You had been contacted by some organizations that would prove to be a resource for you.[00:20:00]

Claire Jeffers: Yeah, because it's a pretty well-oiled machine here in Maine, which is an amazing thing. And we're super lucky to be here. Basically when a baby in Maine who's born in a hospital, refers on their newborn hearing screening that goes into a data system. And so that data system isn't just flagging the pediatrician. It's flagging the Maine Newborn Hearing Screening and this is run by people who have deaf and hard of hearing children who are part of the Maine Deaf and Hard of Hearing community, have a family member, and they have changed their life course to make sure that the access and the information is where it needs to be. So the fact that this state-mandated screening is in Maine is really but then once the screenings are available, that flags a couple of different organizations. So Child Development Services is one of the organizations that reached out to us to establish an initial appointment. We're so grateful that we had that kind of support kind of immediately jump in and contact us. But sure, at the time we're at home with a newborn and people are calling us with names of organizations with different acronyms that we've never heard, and we're kind of trying to keep 'em all straight and schedule things. That was a little disorienting, but ultimately it got all sorted out. We made the appointments. And so the Maine Educational Center for the Deaf and Hard of Hearing contracts with Child Development Services, which is a pretty huge component of the services that we ended up having thereon out. Representatives from both of those entities come to your house to meet you and your child. There's a bunch of forms and evaluations. They're checking for any mobility issues or site issues. They tested his hearing with a big, loud bell behind his head. I believe it was early March. Was just 10, 11 days from the [00:22:00] shutdown. People were just coming over as usual. There were no masks, there wasn't even a concern of anything. I don't think Covid had technically arrived in Maine yet by then. So we started to meet specialists and service providers, and there were a couple weeks where we were like who's the person that we're contacting now, or which one's the person that we're working with for the next three years? But, it takes a couple days, couple weeks to let the

pieces fall and the dust settle. And we're in what's called an Early Intervention Family Services Program with the Maine Educational Center for the Deaf and Hard of Hearing that starts at birth to age three. So, somewhere in this timeline of March 2020, we realized that we have these amazing services free to us, state-funded services, for the next three years. We're just on the very beginning and met our early intervention family services contact. Amy. Had never met her before. Didn't necessarily know exactly what she did and three and a half years later, she's a dear friend of ours and someone we consider an integral part of how well our son is doing, how well we're doing. And I can't say enough about that program.

Diane Atwood: Because of Covid, all of those in-person in-home visits came to a screeching halt, and so everything had to be done online. Did you suffer because of that, do you think?

Claire Jeffers: it was a really, really, really challenging time. Of course, everyone in the world was dealing with their own version of it. In so many ways, I felt so grateful that I had a safe home. I had food, I had a computer, and I had a phone to contact people with. I mean, I was lucky in so many ways. Our baby was healthy, and yet, I do have to recognize the fact that we were also dealing with some additional challenges. it would've, of course, been so [00:24:00] different had Covid not happened at this moment. And, I wanna just say, too, that the timing of everything, so that second follow-up appointment was actually March 11th, 2020. That was a Wednesday. I don't know if everyone remembers this, but the only reason why I do is because after the follow-up appointment at the audiologist, it was the same appointment all over again. Three hours, the baby nursed for three hours, and she actually not only got a severe reading for his results, but she was getting profound readings, which means that he is profoundly deaf. And at that point, we'd had a couple of conversations with specialists. We, I think we'd had at least one appointment with CDS. I had done probably many hours of research and talking to people by then. It was still raw. It was still fresh information, but we didn't necessarily expect that follow-up appointment to give us any different news. So it wasn't the same as that first appointment. We weren't in shock or anything. We were very tired and very exhausted, but at the very end of that appointment, we're still sitting in that soundproof booth and we're packing up our things. We just confirmed the results. He is indeed deaf. And I kind of instinctively picked up my phone to check messages, see if anyone called while we were in the appointment. And there's a news alert on my phone that says the World Health Organization has just declared a global pandemic. And I remember saying that out loud to the audiologist and to my husband and the audiologist said, oh, wow they've officially called it. That was kind of another level of walking out of this appointment with this news that how this is really happening. This is serious.

And sure enough, my maternity leave was set to end the following Monday, so just a few days later. And the first day back from my maternity leave, of course, that was the Monday that all offices [00:26:00] shut down and changed over to remote. So my first day back at work was a remote workday, and I never actually went back to the office where I worked in downtown Portland. And so we worked from home as everyone else did with their children and their pets and their relatives, and we were home with our newborn. And, it was just an unbelievable time, and I don't know how we did it other than we just did the best that we could. We got our groceries, we cooked food, we did what everyone else was doing. We baked bread and okay, we'll get through the next two weeks, the next two months. So, I had never gone through this experience before, both Covid, but also, having a deaf baby. So I didn't know what I was missing. I didn't know that we would typically be able to go to weekly family groups and meetups. I didn't know that there were events and different community opportunities that we could go meet other families, other children. I slowly learned that those were things that would normally be available, but in the beginning, I just thought, okay, well I guess we'll just meet with our service provider over Zoom, and I guess we'll just meet with our deaf mentor over Zoom and start learning American Sign Language. You know, again, you don't know what you don't know, and it's just what you have in front of you. If this were 30 years ago and the pandemic happened, we wouldn't have had Zoom, we wouldn't have had the Internet. I wouldn't have been able to even go to a class to start learning American Sign Language. The classes would've been closed. I would've been so much more isolated and cut off from information. So, while the world was closed for in-person, I was able to access a lot, sometimes too much over the Internet, and certainly talk to people over Zoom and have conversations with people. That's something that I definitely recognized in the moment. At least we had this technology.

Diane Atwood: Yes. At least we did. Can you explain what it means to be profoundly deaf and what you learned about why [00:28:00] your son is profoundly deaf, and there's no one reason why a child is born that way?

Claire Jeffers: I think, potentially, hundreds of reasons why or how which I didn't know at the time. My husband and I, we had never met a profoundly deaf person. We didn't have a relative or a teacher or someone in the community that we could necessarily reach out to. Our son really was the first deaf person that we intimately knew. And there's also different definitions for what it means to be profoundly deaf versus moderately deaf. And ultimately it's up to the deaf person to indicate how they'd like to be identified or what terms they'd like to use. But in terms of my son and his access to sound, being profoundly deaf for him means that he does not have access to any spoken language. The spoken language frequencies are not available to him and furthermore, environmental

sounds for the most part are not available to him. I've been told that a very loud noise, like a screeching ambulance siren right at your ear, would be something that he would be able to hear. Or someone else described it as like a very loud jet engine parked right next to you, and then I've also heard that depending on the person and their experience, some profoundly deaf people can hear a very loud dog barking sitting right next to them or very close to them. So it can vary, but, I think the overarching message is it's really just really loud noises. I do remember one moment when our son was very small. We live in a very old house and one of the doors, if you're not careful or, and you don't catch it in time, it can slam on its own. The window's open, and the wind pushes it, or for whatever reason, it's just a really sensitive door. But when it slams, it's really loud. It sounds like a gunshot. It always would startle me if I didn't catch it.[00:30:00] And I remember, my son was sleeping in the co-sleeper in our bedroom, which is where this door is, and I was walking out of the room knowing that he probably wasn't gonna wake up from me walking out of the room. But I forgot to gently close this door and, of course, it slammed really loudly. And I saw his little body wrapped up in the swaddle kind of shake a little bit. And I remember thinking, okay, so he might have heard that or maybe it was the vibrations. Maybe he felt that maybe it was the combination of the two. But that's generally what I tend to say, just to give people context for what sounds he can access with his natural hearing. But the bottom line, in terms of language acquisition, if a profoundly deaf baby is not accessing speech frequencies, then that means that they are not accessing spoken language. That's when the importance of a visual language comes in because a visual language like American Sign Language, is a hundred percent accessible. The challenge there, of course, is parents who don't have a background with American Sign Language or haven't learned any of it by the time their baby is born are quickly having to learn this language so that they can start providing their child with some vocabulary and with some language access. And it's a long complicated story of how American Sign Language comes into families with deaf and hard-of-hearing kiddos. But for our family, right from the beginning, it was kind of a no-brainer. We absolutely thought that we needed to provide a visual language for him. We didn't know what was gonna be available to him. We didn't know if hearing aids would assist him in language access. We didn't know if cochlear implants were gonna be an option for him. We didn't even really know what cochlear implants were. We had a [00:32:00] very small understanding of what this technology was able to do, but we had no idea if he was a candidate. But we did know that from the very moment he was identified that it made total sense to us that American Sign Language needed to be part of our process.

Diane Atwood: So you've been doing that, learning it, and now he has learned it or is learning it so the whole family signs? Yep. I have a question about the

anatomy of his ear. Yep. Does he have all the parts that we have, and they just don't work?

Claire Jeffers: One of the questions early on, of course, is what caused him to be deaf. That's one of the very first thoughts I had as a new mom was did I do something in pregnancy? Did he have a virus or is there something going on with him? Do we need to get additional screenings? And each family is different in terms of how they approach this part of the journey. But, we did wanna make sure that we got some additional testing and we were given some options as to how to do that. Also, other things that they can look for, you know, if there's, an indication that there could be a syndrome happening. I think at one point we had his kidneys checked. We were also given the option if we wanted to do some genetic testing. So genetic testing can often tell you about any syndromes that the baby has or I think also they tested, perhaps they tested the cord blood for a couple of viruses. So CMV is a virus that can cause deafness in newborns. He was tested for that. That came back negative. And then to get an MRI to see if there was any challenges with anatomy. We wanted to do that with Boston Children's. I think the MRI was scheduled for seven months, so when he was seven months old, which was July 2020. August 2020 is when he was fitted with his first hearing aids and when we received the genetic results. We got a lot of information in the summer of 2020. This was a pretty pivotal part of our experience. We were told that the hearing aids [00:34:00] likely would not give him much access to spoken language but if we wanted to continue to explore the cochlear implant decision that the insurance companies want the child to wear the hearing aids for a certain amount of time to basically prove that they're not providing much. So, there's a couple different steps that we had to go through, but, you know, we also wanted to see if the hearing aids would be of assistance to him. Then we also got the genetic results and we found out that my husband and I actually carry a fairly common gene. I believe it's the Connexion 36 gene. No idea that we both carried this. And, of course, every single person carries all sorts of things and it just depends on who you end up making a child with. So we happen to both carry it and it's a recessive gene. So we passed that gene down to our son. The last time I checked, 50% of babies who are born deaf carry this gene. So it's a fairly common reason why a baby may be born deaf. And then, of course, the other 50% is like hundreds of other reasons, right? But it's a very common what's called a deaf gene. This was a pretty pivotal piece of information for me, personally, just because this obviously indicated that I had deaf lineage. I had relatives I have never met, that I will never meet, who have long passed, but who were likely deaf. And there was something about that that was meaningful to me. And, also, with the understanding that 25% of the babies that we may go on to make will be deaf. That's the percentage with recessive genes. Never anticipated any of this. So, the MRI showed that his anatomy all looked typical, no malformations, everything was there, you know. He had a

healthy-looking auditory nerve that ran from his brain down to his cochlea. He had two cochleas for each of his ears. So everything was there. This gene just prevents the sound from being transmitted to the [00:36:00] brain somehow. And so those are the pieces of information that we got in summer of 2020.

Diane Atwood: So, having that information, especially from the MRI, it gives you options that you might not have had given other results. Right? Yeah. It gave you the option of being able to decide whether you wanted him to have a cochlear implant?

Claire Jeffers: It did. That MRI did indicate that he was a candidate for cochlear implant surgery. By that time we had done a fair amount of research and talking to lots and lots of people on the entire spectrum of deaf and hard-of-hearing experiences. People who had used technology, whether it was hearing aids and or cochlear implants, people who didn't have technology access and grew up with American Sign Language, and everything in between. Any combination of all of those things. Some people who grew up orally being taught to use their breath and the vibrations on their neck to use their voice despite not being able to hear at all. People who read lips is less common, but some people can do it slightly better than others. It depends on the person, and not every deaf person can read lips. I think that's a very common misconception. But we talked to, and we researched a lot in these months. And we also found out a lot about cochlear implants and what they're potentially capable of doing. Downsides of the cochlear implants, the risks of the surgery, risks of the implantation of the devices. And also the implications of how this would potentially steer our child in a certain direction. Meanwhile, while all of this was happening, we're also learning a language. We're actively learning American Sign Language. We're meeting with a deaf mentor who's teaching us sign language over Zoom at least one hour a week. And then we're doing our own online classes at the same time. Now remember, it's still Covid, so it's all [00:38:00] online. I'm doing my own classes on the weekends at night. I'm watching YouTube videos. I'm downloading different apps on my phone so that I can look up different words to understand how to sign words. That's all happening, as this information is coming in and at this point, we knew that the cochlear implant surgery would be about a six-hour surgery. And the thought of my child going into a six-hour surgery, a cranial surgery where they drill into his skull and essentially partially remove their ears was incredibly hard to think about and was really something that I very much grappled with on a, not only daily basis but probably hour to hour basis for many, many, many months. It was not something that anyone wants to do, you know? It wasn't exciting to me, it wasn't something I looked forward to. I didn't really care if the devices potentially would give him access to my voice. That wasn't enough for me to feel comfortable with the prospect of this surgery. And I say this because I'm

sure other people have felt this way. Certainly, there are parents who have different experiences and different perspectives on this, and that's okay. This was just my perspective on the choice of cochlear implants. Um, so I really grappled with whether or not I wanted to do it, and my husband felt the same way. It took a long time for us to make a decision and, ultimately, he did have the surgery and it was election week 2020. People may remember election week 2020 was quite the week. It was a very, very, very tense week for this country, maybe even the world. And it was just extremely stressful. But I wanna go back to how we ultimately made this decision. And for me, one of the biggest reasons was because I wasn't sure how long this thing was going to last. How much longer are we [00:40:00] gonna be locked inside? I don't wanna be dramatic, you know, we weren't locked inside, but we were not able to go, we weren't going places. Certainly, we weren't going to grocery stores, and we didn't have access to the deaf community or other families with deaf and hard-of-hearing children. We weren't sure what education was necessarily gonna look like. It was even hard to think about for our 8, 9, 10-month-old baby, but we weren't sure what the world was gonna hold. And while we were doing our absolute best to learn this visual language, this amazing language that gives you access to it was slow going. We were nowhere near fluent. I still am not and we felt like we were giving our child pieces of language, but not a full language. We just didn't know where this was headed. So, for me personally, one of the biggest points of my decision-making was I want him to have as many opportunities as possible, and if we could provide him with that, then that's my job. I also, at that point, very much knew and understood that no matter what we decided, ASL could always be part of our life and part of his life and it didn't mean that we had to choose one or the other. We could have both. And that was also a really, really comforting choice to be able to make. Basically not have to choose and have both. And so we scheduled the surgery.

Diane Atwood: And he was not even a year old when he had that surgery.

Claire Jeffers: 10 months. Yeah.

Diane Atwood: 10 months. So he has the surgery at a time when kids are really beginning to access language.

Claire Jeffers: Oh yeah. We definitely had friends whose infants were starting to babble and form, you know, mama-like indications of early spoken language. And I should say too, that at 10 months of age, my son was not only signing, but he was understanding the signing that we were able to do. So he was signing mama, he was signing dada, [00:42:00] he was understanding short sentences that we were able to sign. So, that was extremely encouraging to be able to do

and to witness for him. While certainly some of his hearing peers were starting to babble and say Mama and Dada, I was also having those experiences just in a different language. I think in the very, very early days of his identification, I thought, ugh, it's going to be really hard for me when my friend's kids start to talk or when they start to say mama or I love you in the spoken language. And actually what ended up happening was because I had those experiences, it just was in a different language than what I expected. And, not only that, but he was actually, from a language standpoint, ahead of many of his hearing peers because children, both hearing or deaf and hard of hearing can access visual language much earlier than spoken language. So, his brain was just absorbing everything that we were giving him. And he had a bigger language vocabulary, so it was very rewarding, it was very satisfying, it was incredibly encouraging, and it solidified our commitment to ASL knowing that no matter what happened, whether the surgery went well or not, whether or not the devices worked, whether or not his devices are on or off, whatever may happen, this visual language could always be accessible.

Diane Atwood: So he got the cochlear implants. He heard your voice for the first time? Was it as dramatic as one might imagine?

Claire Jeffers: No, and it was actually something that we knew to prepare for. It's not until a month after the surgery that he's what's called activated with his exterior devices. So, he has his surgery, he needs to recover from this very intensive cranial surgery. So we're back home in Maine. He recovered after about 10 to 12 days. He was doing really well and he kind [00:44:00] of reverted back to waking up five times a night for the first week after surgery, which was really tough. It's not until a month after surgery that we go back to Boston to activate his devices. And that's technically when he has access to our voices for the first time. While he might technically be accessing the sounds that make our voices and make these words, his brain has no idea what the sounds mean. The same way that I could start signing to a one-day-old baby and that's great, but they're not gonna know what the signs mean yet until they start seeing the signs over and over and over again after days and weeks and months. So the first day of hearing, the brain doesn't know what that means. It's just a new sensation. a new experience, and sometimes it can be really overwhelming and unpleasant for the child. So we knew all of that, and it was not an appointment where we were. I wasn't crying. I wasn't popping champagne. It was just an appointment where we knew that we're gonna just take this very slowly, one step at a time, see how things are going, and for our family, while we're in awe of this technology, completely amazed by what this technology does, we also want him to know that it's amazing that he also has visual language. You know, it's not one is better than the other. It's just that they're very different experiences, different choices, and different opportunities. And again, at this

point, I'd had so many interactions with him as a mom, both with language and just with love and attention and being close together all the time, that hearing my voice ultimately was not something that was that important to me.

Diane Atwood: I know you have to scoot because you have to go and pick your son up at school, but please give me a few minutes. Describe how your son is [00:46:00] now. He's three and a half years old. He's in preschool. He has his cochlear implants. He's got access to language and so much more. It was worth it?

Claire Jeffers: Yeah. You know, it's been such an amazing experience. He's doing awesome. He does like his, we call it his sound. He likes to have it on. He also likes to have it off. He takes it off when there's a loud noise that he doesn't wanna hear. He sleeps without his devices on. They often fall off when he has a hat on or a helmet on. Sometimes when he's really angry, he rips them off in anger. But he's doing great. He's bilingual. He has English and ASL. He signs, he talks with his voice, and he chooses which one he wants to do at any time. And we certainly would love for him to continue to do both. He is in an ASL immersion program. Throughout the day, he has plenty of access to English and spoken language. So he's getting really a bilingual education at three years old, which is incredible that that's an opportunity that we have here in Maine. And he is just an energetic, curious, bright, super-loving, and hilarious three-year-old.

Diane Atwood: And for a woman who was worried about being the kind of mom her son would need, I would say you have surpassed that.

Claire Jeffers: Thank you. Thank you. That's really generous. It's amazing what we can all do. And this has been a huge, huge turning point for both me and my husband, as individuals and together. To do this together was also a really incredible experience. It's made us super strong. It's made us very in awe of what we're able to do for each other. I think many moms feel like they can do anything once they have a baby. And I 100% believe that they can. I feel like not only that, but on top of just doing everything [00:48:00] that we've done for our son, I honestly think that anything's possible. It just takes a lot of work, a lot of commitment, a lot of resources. And we're super lucky. My husband and I are lucky that we have the resources that we have. We have community, we have the opportunity to take classes. We have the support, family, friends, community support. We live in a city, so a lot of things are close by and that makes things more accessible. People who live in more rural places, it can be more challenging. So we also recognize that our particular situation was just super lucky. With all of that and just tenacity and grit and believing in yourself. It

sounds super cheesy because it is, but that's the only way for me to really explain it because, before all this, I wouldn't have imagined that I would be able to do this. And so to look back and see that not only did I do it, but I continue to do it. and also my son is living proof that he not only is doing okay, he's doing amazing. It's a really amazing thing to witness.

Diane Atwood: Well, thank you. Thank you for your inspiration and your love. It continues to take a lot of love.

Claire Jeffers: You're right. Well, thank you so much, Diane. This was such a pleasure talking with you, and thank you so much for taking an interest.

Diane Atwood: Absolutely. Now go get your boy.

Claire Jeffers: Right. Thank you.

You have been listening to the *Catching Your Memories* podcast. My guest was Claire Jeffers. She asked me to emphasize that cochlear implants are just tools. They aren't a fix or a cure for deafness. She and her husband, Ben, strongly believe that with, or without them, their son would have been just fine. But they are grateful they had the choice. If you would like to read a transcript of this episode or leave a comment, go to [catching your memories dot com](http://catchingyourmemories.com). This podcast was created, produced, recorded, [00:50:00], and edited by me, Diane Atwood. *Catching Your Memories*, the interview of a lifetime.