



SoundBites Podcast Transcript

Episode: Balancing Sound and Silence: A Personal Story of Childhood Hearing Loss

Dr. Dave Fabry:

Welcome to Starkey Soundbites. I'm your host, Dave Fabry, Starkey's Chief Innovation Officer. We're nearing the end of summer. With that, of course, is the rite of passage when kids get ready to go back to school or start school. Today, on the podcast, what we want to do is talk to the parent of a child with hearing loss, and I'm delighted to have my friend and colleague, Nicky Hemann, who works at Starkey, and her daughter Kaylee was born with hearing loss. We'll talk about that a little bit today and in this podcast. Thank you for joining us.

Nicky Hemann:

Thank you for having me.

Dr. Dave Fabry:

I know that with this topic for you, it's a very personal one. We know that while a lot of the focus these days is on hearing loss in the aging population, and this summer, there were some of the findings that were reported from those with untreated hearing loss and cognitive decline. Another very important but often overlooked area, particularly in the US, is hearing loss in infants and children and congenital and early hearing loss. This is an area that you and I have talked about a bit, and I'm delighted that you are willing to come on the podcast and talk a little bit about that today.

Nicky Hemann:

Well, thank you for having me, and I'm happy to share and see who we can help.

Dr. Dave Fabry:

Exactly. First, let's talk about you. Describe your role at Starkey.

Nicky Hemann:

Yeah, so I am in on the HR leadership team. I have a business partner role. I support different executives in the organization. My goal is to always work with the executives and challenge them to think about their people in different ways and how can we develop them or use them differently or continue to advance not only our own capabilities, but our people that are working in the organization.

Dr. Dave Fabry:

I think that's perfectly suited to skill sets that you have to be an advocate and advocate for yourself in your work environment, but also in terms of the case of your daughter Kaylee, in terms of her education, and also with the unique situation with significant hearing loss and thinking about how it is that that might impact her educational experience. Let's talk a little bit about Kaylee. How old is she?

Nicky Hemann:

She turned three a little bit ago. She loves to sing and dance and run around.

Dr. Dave Fabry:

All things young kids do. I just became a grandfather-



Nicky Hemann:
Congratulations.

Dr. Dave Fabry:
... Earlier this year. And so I'm experiencing some of that all over again, except as a grandfather, you get to see their smiling faces come in, but if they cry or this is she's just an infant, Charlotte, my granddaughter, then she can go back to her mom too.

Nicky Hemann:
Yeah, exactly. And you get to sleep through the night.

Dr. Dave Fabry:
I get to sleep through the night and just try to spoil her the best I can.

Nicky Hemann:
Win-win.

Dr. Dave Fabry:
But on a serious note with children and grandchildren, I think a lot of people may not be aware that in the US in most states like Minnesota, if not all, there is a mandate that some form of screening and universal screening of newborns take place before the parents leave the hospital. I assume that that was perhaps when you first were told that Kaylee might have hearing loss.

Nicky Hemann:
She failed both of her newborn hearing screenings, and I was told she was born via C-section. That was normal. Don't worry about it, just have a follow-up appointment in a couple of months and I'm sure everything is fine. That was our first maybe opportunity to learn that maybe something was different with my daughter.

Dr. Dave Fabry:
You had had no prior knowledge or there were no risk factors that you were aware of. This kind of caught you, like it does for many parents. It's estimated between one and three per thousand births have a genetic hearing loss in the case of individuals born with that genetic complication. Then we also know that there are other conditions, elevated temperature and other things that can cause hearing loss after birth. When you were in the hospital, they likely did auto-acoustic emissions, I'm guessing, is the first level screening. We'll get a little wonky here, but given that many of the people listening to our podcast are hearing care professionals, the first line of screening in many cases, you said she failed both screening initiatives. Were they both in the hospital?

Nicky Hemann:
Yeah, they repeated that.

Dr. Dave Fabry:
Yeah. They probably did auto-acoustic emissions, which is matter of just putting a sound in the ear canal and literally measuring an echo that comes back in the event that the baby has normal hearing. It really tells a little bit of screening level, mild to moderate hearing loss. It's a screening measure, first level



screening that doesn't give you a lot of detail other than to say, "Yeah, it's likely there's a problem." The second level screening is probably auditory brainstem response, where now they're putting a sound usually clicks or sometimes tones into the ear and they're measuring the neurological projection.

Nicky Hemann:
Yes.

Dr. Dave Fabry:
That one you were familiar with, but it's probably auto-acoustic emissions is what most people in many facilities are using as a first line screener.

Nicky Hemann:
Okay. Yep.

Dr. Dave Fabry:
Followed by ABR.

Nicky Hemann:
Yep.

Dr. Dave Fabry:
It's interesting, one of the issues that we've seen, and we really owe our profession, my profession owe a debt of gratitude to Marion Downs and others before who really stressed the importance of newborn hearing screening. If there have been any detractors, it has often been that it's not just the screening that's important, but then what happens after that? The urgency is often a challenge. If you're comfortable, we talk about hearing loss in any age is often an invisible disability. There are some certain hearing losses and syndromes that are accompanied by maybe a deformation of the external ear, something you can see. In most cases, it's an invisible disability.

Nicky Hemann:
Yep. Absolutely.

Dr. Dave Fabry:
Now with no prior concern and with that first level and then the second level screening, while you're still recovering from the C-section and you're told there may be a hearing loss without really knowing the degree of hearing loss and saying, "In the next couple months, do something." Can you talk a little bit about how you and your family dealt with that sort of very stressful news on otherwise you have this perfect child. There's no visible disability?

Nicky Hemann:
Yeah. It definitely was an anxious period for us. My daughter was born in the midst of Covid, so I wasn't sure if they were putting off the follow-up appointment because people were trying to avoid doctor appointments or was it really not a big deal or what was it? So I remember calling them up and asking like, "Hey, are you sure two months out? Shouldn't it be sooner?" They were like, "No, no, that's fine. Don't worry about it." For two months, my husband and I are like clapping really loud-

Dr. Dave Fabry:
Banging pots.

Nicky Hemann:
Banging pots, dropping things on floors to see if she had any kind of reaction. Of course we probably saw some because we wanted to see some, or maybe she saw the movement or felt the vibration of the loud noise we were doing.

Dr. Dave Fabry:
Yeah, there is a reflex, the moral reflex you're probably familiar with, or you became familiar with this where they go out in response, but typically just to a very loud sound.

Nicky Hemann:
Yes.

Dr. Dave Fabry:
You lose, again, that subtlety. Then complicated additionally by Covid, as you say, where many clinics were unable to either see patients at all for a while or to certainly see the load that they needed. Now the clock is ticking. I would imagine knowing you immediately went into overdrive with starting to look at what was the impact of delaying or what to do next. Is that correct? You kind of start looking, going to Google, Dr. Google.

Nicky Hemann:
Yes. Oh, such a bad idea. But yes, started going down the Google ... There's so many different rabbit holes you can go down there with hearing loss and what is it and what could it be? Is it genetic? Is it ushers? Is it, what is it? Yeah, just at some point I just had to go like, "Nope. Okay, we're just going to go to the appointment and we're going to see."

Dr. Dave Fabry:
When did you then have the first follow-up appointment for more diagnostic testing?

Nicky Hemann:
At two months, she had her ABR.

Dr. Dave Fabry:
Okay.

Nicky Hemann:
That is when she had no response to any of the stimuli. I think they went as loud as a rock concert to try and add a pictogram to the audiogram to make it understandable for parents and non-hearing professionals. But yeah, she had no response at all. I just remember, and even though I'm trying not to, but just grieving. What do you mean? For two months she hasn't been able to hear anything? You're telling me that my daughter has a severe to profound hearing loss? What does that mean? I don't know sign language. Can she have hearing aids? Just all of the things that just, did I do something wrong? All of those things.

Dr. Dave Fabry:

Yeah. It suddenly just rocks your world. It's sort of in the Baz Luhrmann wear sunscreen moment where he talks about don't worry because worrying isn't productive be, it's like trying to do algebra problems while you're chewing gum. It's sort of a mindless exercise. But the real things that impact your life occur and come out of something like this. He talks about a random Tuesday afternoon, but I can imagine whatever day that was, that rocked your world.

Now, for some of the professionals I've had the opportunity to work with parents and to be involved in breaking that news. I can tell you that on the professional side, I mean it's not my child, but it's not any easier to break that news when this phenomenon of my perfect baby, my perfect child, and to have to break that news is very challenging. One of the things for professionals that I could advise, and I'd be in curious about you, is that once you get to the point of saying, "Your child has a severe to profound hearing loss." Stop talking. Because I would imagine at that point, like you said, you just sort of shut down.

Nicky Hemann:

I shut down.

Dr. Dave Fabry:

You didn't hear anything else after that.

Nicky Hemann:

Nope. Those words are, they something in the hearing community and to hearing professionals, but I was like, "What does severe to profound mean?" Is she deaf? Can she hear something? Yeah, I would say stop talking. Let us process that very big bomb that we just got dropped on our lap and just be there for us and help answer our questions as we are ready to start asking.

Dr. Dave Fabry:

Yeah. Because sometimes, one of my mentors would often schedule a second appointment after the news gets broken and then say, "Do you have any immediate questions?" But then otherwise, stop telling me things because I'm not thinking clearly if I'm on the parent side and schedule another appointment, give them some opportunity to deal with the weight of this and then come back with questions and issues. Was that kind of the way you had it?

Nicky Hemann:

And I have definitely even asked for additional appointments like, "Hey, can I have one now that I've kind of processed some of the emotions of it and I'm not crying." And all of the things. Yeah, for sure.

Dr. Dave Fabry:

It's an entirely different clinical experience and emotional experience from in many cases seeing an older person start to come to grips with the term that they have hearing loss. I do think that we have an age related prejudice related to hearing loss in this, the sense that for children, we do universal newborn hearing screening. I think that we need to raise awareness for hearing loss so that when you get the Welcome to Medicare exam, that you get an actual hearing test just so you know where the baseline is moving forward. You're likely to have hearing troubles, but this notion of giving people time to come to grips with it, but now the unique situation with a young child, the clock's still ticking. Now we know there's a correlation with untreated hearing loss and cognitive decline in the elderly. Let's talk a



little bit about the speech and language impact of getting the language in to a young child as soon as possible. Now two months, you get the ABR.

Nicky Hemann:

Yep.

Dr. Dave Fabry:

You deal with the gravity of this situation.

Nicky Hemann:

Yep.

Dr. Dave Fabry:

What's next?

Nicky Hemann:

A blur of appointments. We met with a pediatric ophthalmologist. She had an ultrasound of her brain. She had an EKG of her heart. We did Cts and MRIs. We met with a neurologist. We did genetic testing. We did all of these things. Then we finally figured out to test for a virus called CMV. It wasn't until we got those positive results back that we realized that she's deaf or severe to profound hearing loss because of a virus.

Dr. Dave Fabry:

Yeah. Going through all of those other tests to look at the comorbidity, which can occur with syndromes, with conditions that can be present at birth or shortly after birth, is excruciating because now you're waiting for the other shoe to drop, no doubt. Waiting to see what else are we going to have to deal with in addition to the hearing loss. The hearing loss is enough, but then looking and ruling all those things out, I can only imagine what you were going through.

Nicky Hemann:

Yeah. Okay, she can't hear, and now you're telling me she needs an ultrasound of her brain. Is there things wrong with her brain? Is she going to need heart surgery? The eye doctor that we went to was one of the first appointments. My daughter has pigmentary retinopathy, so she has some damage to her retinas. The eye doctor immediately jumped to, "I think she has Ushers syndrome." For a while there we were operating under the assumption that she probably would have Ushers Syndrome, which is what Helen Keller had, which means she would for sure lose her sight. She would not only be deaf, but blind as well. It wasn't until we did genetics and ruled out, "Nope, it's not Ushers." And we were still waiting for that CMV test. That didn't happen until later that we were like, "Okay, well now what is it? We don't have the genetic component. It's not Ushers, it's not any of these other things." It was a very scary period for sure.

Dr. Dave Fabry:

Again, for the professionals listening in here, I think the pro-tip out of this is remember that you're not dealing with textbook cases anymore, and you shouldn't just throw out options. Because as a parent in going through this, you're going to go down every rabbit hole that is teed up for you. Just use the grace



to remember that you're dealing with humans. Humans, we're going to be emotional and we're going to go down rabbit holes.

Nicky Hemann:

For sure.

Dr. Dave Fabry:

Now diagnosis of severe to profound hearing loss as a result of CMV.

Nicky Hemann:

Yep.

Dr. Dave Fabry:

Then what was the next step? Was it hearing aids? Did you begin the discussion regarding cochlear implants?

Nicky Hemann:

We started hearing aids almost straight away.

Dr. Dave Fabry:

How old was she?

Nicky Hemann:

Probably three months old.

Dr. Dave Fabry:

Yeah. That's unfortunately still not the norm in many cases because of the delays that occur in getting appointments scheduled, especially with Covid then, and then also still denial is a powerful deterrent to action. I applaud you for then at three months really beginning that process. Talk about that.

Nicky Hemann:

Yeah. I still have her little ear molds and the different colors. You get to pick out the color. That's a little bit of help, I guess. Because I was like, "Oh, she's a girl. I'll do pink." Or whatever. Now I'm like, "Okay. Now I have to use these hearing aids, this technology that I know nothing about, I've never used before." I have to try and get my infant to wear them who's starting to be on the, "Oh, I've discovered my ears." Phase and pulling on them and pulling them out and learning very quickly that if the seal isn't sealed correctly, then all mom hears is that squealing noise. Yeah, it was definitely a learning process for mom and dad.

Dr. Dave Fabry:

This was all prior to when you joining Starkey.

Nicky Hemann:

All prior to me joining Starkey.



Dr. Dave Fabry:

Chicken and egg. Then, was there a pull towards working for Starkey as a result of the experience with Kaylee or did-

Nicky Hemann:

Absolutely.

Dr. Dave Fabry:

Yeah. I figure it becomes then a passion.

Nicky Hemann:

Yeah. I mean, my whole world has become about helping her hear better and live better and learn language and all of the things. When there was an opening at Starkey doing what I love to do professionally, I was like, "Well, this is a no-brainer." Like how often do you get to do what you love to do in a company that is also your personal passion? Now that I've been here about a year-ish, I'm learning that it's not so rare because there are a lot of people that share the same passion or have some connection to hearing loss and also get to work here. It's kind of cool to be more involved in the community.

Dr. Dave Fabry:

Yeah. ever since my daughter was this tall, I was saying, "Find your passion." And she's like, "Dad, I don't understand what that means." But I think it's when you can align what you're good at professionally with something that you love to do and then also the impact factor and aid able to then be an advocate for Kaylee and understand and also translate that into other situations that may come up where you might be involved in advocating for other children. Okay. She was fitted, and?

Nicky Hemann:

No impact. The hairs in her ears never grew. We tried hearing aids, we did the sound booth test and the audiologist, no response, although they did prepare us to potentially expect no response with that kind of hearing loss. Then, we went through an anatomy MRI to see if she was a cochlear implant candidate, and she was. We made the decision to implant her with cochlear implants, and she was implanted at 9 months and activated at 10.

Dr. Dave Fabry:

Wow, fantastic. And bilaterally?

Nicky Hemann:

Bilaterally. Yes.

Dr. Dave Fabry:

Now is she your first?

Nicky Hemann:

She's my second.



Dr. Dave Fabry:
Second. Okay. How old is her older sibling?

Nicky Hemann:
He will be five pretty soon.

Dr. Dave Fabry:
Five. What's his name, if you don't mind?

Nicky Hemann:
Asher.

Dr. Dave Fabry:
Yeah. How did Asher handle ... When you were going through the early stages of this, he didn't really probably get it.

Nicky Hemann:
No. I mean, he was really excited to have a sister and a baby, and he is the most protective, helpful big brother, which is great. But just hearing him talk to her kind of broke my heart in the beginning a little bit because I'm like, "Oh my gosh, he has no idea she can't hear him." Watching that was hard. Even now that we're older, and anytime she's not wearing her processors or cochlear implants, we have to remind him like, "Hey, Asher," we call them her ears. "her ears are off. Remember, she can't hear. You have to sign so she can understand you." Even then, it can be really hard to remind him and remind us, and even mom and dad have to remind each other sometimes.

Dr. Dave Fabry:
You mentioned sign language, and so you then undoubtedly learned sign language yourself.

Nicky Hemann:
We are trying to learn, yes.

Dr. Dave Fabry:
I think that's sort of an interesting point in this too. We talked about universal newborn hearing screening, the need for action, and you were right on timeline, with getting as short a delay, advice for other parents who might be listening to this is really the screening is important, but then getting the follow-up testing, the diagnostic testing, and then the proper prosthetic devices, whether that's hearing aids or cochlear implants, trying to just keep marching forward knowing that all of that other host of emotions, grief and all of that that comes along with it, but to keep moving forward because the clock is ticking on speech and language development and trying to get that sound in there. But more importantly, to get the language in there. You mentioned ASL, so you're learning ASL and your son, has he picked up ASL too?

Nicky Hemann:
Yep. He's learning it with us. We have chosen a bilingual, bi-cultural approach, which is not for everyone and that's okay. One of the reasons we started even in the beginning, even if you just do baby sign is, to your point, she wasn't receiving language through voice, through the spoken language. We wanted to

give her as much language as we could get her. Our only option was visually. Started with baby signs of more and all done and milk and the easy things. Yeah. We just continue to try and even now give her as much language in both as possible so that she can continue to acquire. During this, I think it's zero to five is the critical language period and continue to develop cognitively.

Dr. Dave Fabry:

It's really commendable that you ... Because really the way we've talked in the past, you didn't want to make the decision for her. You're choosing with the implants. If hearing aids have been able to help, you would've been fitted with, I know a manufacturer of hearing aids that had we been able to reach that, that would've been a great solution. But with no measurable hearing under ABR or behavioral testing, really the choice was kind of made for you. But then still wanting to get speech and language in there and marching on with that. I remember one of our early discussions was that you didn't want to choose for her whether she chose to participate in the oral world or sign language world. You're giving her and committing with you, your husband, your son, to try to give her that opportunity to when she gets old enough to choose what she's going to use to communicate. Or perhaps it will be both and continue to be both, but it's interesting.

Nicky Hemann:

Yeah. We found that there are all these things that I knew very little about and things like hearing fatigue that I can't relate to. It just felt only natural that I should give her as many options as possible and set her up for success so she can tell me which language she wants to learn in and which one can supplement the other or how she wants to communicate because I have no idea how she's going to respond to sound or if she's going to love it or hate it. We got really lucky, she loves it.

Dr. Dave Fabry:

Yeah, I mean, it's a tremendous commitment and a tremendous gift that you've given to her to give her the opportunity to make that choice when she gets older as to how it is and where she chooses to communicate through oral, through manual, through both. I would imagine you've had plenty of armchair quarterbacks along the way kind of advising you one way or the other. I think that's another issue is that then with this very challenging diagnosis you got lots of opinions, everyone has an opinion. You set a course and stayed deliberate to that, and you were a strong and continued to be a strong advocate for her. I commend you and your family. Given that we're going to be back in school now, now Kaylee's still just three. I would imagine now, is she in any sort of formalized or play? Talk a little bit about groups that she might be in to help with that engagement with other kids, with adults, with speech and language development. What are you doing?

Nicky Hemann:

So we're not at kindergarten or grade school. We're not at those places yet. But, we still are doing the education plans. We're still working with our school district to develop goals and measure her progress. With our bilingual approach, she goes part-time to an oral school in Roseville that takes time to help her learn how to hear and speak. Then, she goes part-time to the deaf school in St. Paul that helps her learn how to sign and communicate visually. We're doing a hybrid approach right now. Then, my hope is by the time she hits kindergarten, she'll be able to tell me her preference for schooling, and we'll go from there.



Dr. Dave Fabry:

Awesome. Any advice that you have, I would imagine so like you said, you're not in kindergarten or elementary school, but you have neighbors and other kids playing with her. Any advice for family members or how to approach the subject of hearing loss and use of hearing aids or cochlear implants with family, with neighbors, with neighbors' kids? Any counsel, words of wisdom?

Nicky Hemann:

Yeah. I would say don't be afraid to speak up for your kid and just be upfront and start the conversation like, "Hey, those are my daughter's cochlear implants. They help her hear. Her ears don't quite work." And then for those out there that don't have the exposure to the hearing world, I would say don't be afraid to ask questions. Right? Seek to understand, seek to learn, because it's an awesome community. The more we know, the more we can help each other.

Dr. Dave Fabry:

Yeah, I think to borrow the old phrase, it does take a village, and I think it does take a village thinking about family and the extended family and community and the educational community. What do you see, I mean she's three now, so her personality is already developing in terms of her sense of humor, the things she likes to do that you shared. What do you see for her future?

Nicky Hemann:

She is bright. Every time we hit a milestone or a challenge, we push hard to give her the additional services she needs so she could meet it. Then every time she beats that milestone. Every time she just blows me away and she's just a bright ball of sunshine. She'll do it with a silly smile on her face while dancing. "Yes, I can say that phrase. Absolutely, mom. Why would you even question that?" I have stopped trying to predict what she will do and just kind of let her take charge, because that's kind of her personality.

Dr. Dave Fabry:

Yeah. You're not only teaching, but you're learning.

Nicky Hemann:

I am learning a ton.

Dr. Dave Fabry:

That's awesome. Can you share a particularly memorable story related either with her hearing loss or something she perceived ... It's our differences that make us better? Anything that came as a result of her hearing loss or use of her implant, or any memorable stories that you care to share?

Nicky Hemann:

Yeah. It was probably the first snow in 2021 after she had been implanted and activated. I remember taking my kids to the window and being like, "Oh, look, do you see the snow outside? It's on mommy's car. Do you see it?" I remember looking at my daughter, Kaylee, and she pointed to her nose and she said, "Nose, nose." I go, "Why is she saying nose? Oh no, I'm not saying nose. I'm saying snow."

Dr. Dave Fabry:

Oh.



Nicky Hemann:

Because they kind of sound similar and to somebody who's very new to language and sound. I remember just crying, being like, "A, she understood me, but B, then she also misunderstood me because she thought I was saying nose and not snow." And just kind of came to this realization that I'm going to have to be very articulate in how I enunciate and continue to make sure that her and I are understanding that we're saying the same thing so that she can continue to learn. That's one that always kind of stands out to me. Happy nose day.

Dr. Dave Fabry:

I love it. I love it. Yeah. Nose day in the future. They get to stay in from school.

Nicky Hemann:

Yes, exactly.

Dr. Dave Fabry:

Well, I really thank you for sharing your journey and Kaylee's journey with hearing loss. I know that there's a lot of important information that you've shared for professionals, for potentially parents who are similarly going through, some of them going through similar process with this and some of the guidance and advice that you've given I know will be helpful. I thank you for doing that with and sharing us your story on Soundbites today.

Nicky Hemann:

Thank you for having me.

Dr. Dave Fabry:

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