Transcript

[Introduction music]

Hanne

Hi everyone and welcome back to the Hear Here Podcast! This is the podcast where we explore the science and the stories behind hearing and hearing loss. This is already season 4, and today I have the honor of hosting the introduction episode! My name is Hanne Bartels, and I'm a PhD student here at Archies Cochlear Implant lab. And to help kick off this new season, I'm joined here today by my supervisor Dr. Karen Gordon,

[music]

Hanne:

So Karen is a senior scientist and audiologist at the Hospital for Sick Children. Welcome Karen!

Karen:

Thank you, Hanne. It's so nice to do this with you.

Hanne

Yes, I'm also very glad to be here! So this is the start of season 4 and in the previous seasons you have spoken with experts such as ENT surgeons, audiologists and researchers who have helped the listeners understand the science behind hearing loss. But in this season, our listeners can expect something a little bit different and very exciting. So I was wondering if you already want to give them a little sneak peek of what they can expect?

Karen

Sure, I'm happy to do it. You know, the just to give a little bit of background to the Hear Here podcast, is we started in the pandemic because as scientists and people working in a

community thinking about how to make it easier for people with hearing loss to get access to sound or to gain language. All of these things. We usually get together at conferences. And so during the pandemic that was not possible and we were doing everything online. But I missed these discussions that I would have with really smart people about the things that they were working on. And so that's how the podcast started in terms of the idea. But the important thing were the people who were working with me on this. And these were amazing group of young people who had a different experience than I do. Of course I come to this community as somebody interested, but I don't have hearing loss. Maybe I'm getting hearing loss as I get older. But I don't have hearing loss myself. I've worked so many years with young people who have hearing loss, but these were students who are now becoming young adults, and they were doing university degrees and trusted in supporting the community, and they could do it in a very different way. Because they had the experience of living with hearing loss and using the devices that we are interested in in terms of trying to help to provide sound. Or they were living with a sibling who was using these devices, so I felt like this group had a lot of. Just really important insight that they could help me with this podcast and so we started out, you know, talking to other scientists and then the Hear Here podcast team would look through all of the episodes and tell me, yeah, this is interesting. This is not interesting. This is what we should include. This is what we shouldn't. Then we also had our amazing co-host Dr. Blake Papsin and Dr. Sharon Cushing, as you know, people to chat with about, you know, what we were hearing because they we worked so closely together here at the hospital for Sick children. And it was fun.

Doctor Papsin wrote the music for the for the podcast, and so we put it together and it was great. And they, like I said, the team of these young people. First of all, they knew how to put a podcast together. So the editing of the audio and like where the music should happen and all of that stuff. I had no idea. Even loading it onto this, you know, where do I put it? Spotify and Apple and iHeart, right. I didn't know all of these things about where to put them. And so they helped me out with that. The following seasons, you know, we spoke to more people and you'll probably notice that they're all women in science in our area. And so that was fun for us. Just to like, take a look at the prominent people who are really doing such good work across our community.

And that was our season 1 and 2 and then season 3, the Hear Here podcast team said, well, we're interested in a career that's in a related field. So we want to talk to people. That you might not have thought of like people in the profession, audiologists, students, ENT's you know, so. So they really carried the season 3, and then when we got to season 4, I thought. They were such good interviewers. I mean, they really asked such beautiful questions and the discussions were so great in season 3. And I said, you know what? I really want to hear, just directly I I've learned so much from just working with this group that I thought it would

be really important for anybody out there listening to these podcasts to hear directly from them, and also because they've become a team, you know, people work together, that those discussions could happen in a group. And that group discussion, which is weird online right when we're recording these podcasts, we're not together. We're all virtual still, but they actually worked. So your original question, I know it was a long way of getting to your original question, which is what do we what can we expect. Yeah. We can expect. That this Hear Here podcast team shines. You're going to hear from really incredible young people who have lived in their family or themselves or whatever it is with hearing loss. And you're going to hear it from them. Just what they think about it, what they've been through, what they, you know, would advise other people about experiencing hearing loss and working through some of those challenges and what worked and what didn't.

Hanne

Okay, well I for one thing that this is a very wonderful idea and I'm very excited to hear what all these wonderful young women have to say. Because as you said, there is no one who can better explain the challenges of hearing loss as people who are actually facing these challenges or are very close to people who do. Actually I don't know if I've ever told you, but I grew up with someone who has hearing loss. I lived with her until I was 12 years old, and she passed away. And she was bilaterally deaf.

Karen

Oh, I did not hear this story before, Hanne.

Hanne

Yeah, I I wasn't sure if I've ever told you so. Yeah, she is the great, great aunt of my grandfather. But well, I just called her the Dutch word for "little aunt". Her story is a bit different of what we usually see because she had normal hearing up to, I think 50 years old, something like that. And then she lost hearing in both ears

And back then, there were no cochlear implants yet, or at least she wasn't eligible for them yet, so she didn't speak any sign language either, so he was always writing down in little booklets. And like, try. We had our own kind of sign language. We had some like signs that you would understand and. So it's always like seeing the struggles that she faced. I really think it's important that the world knows.

And I'm really excited to hear from these young women how they handled these challenges and what the specific struggles were that that they came across and how they solved those or like learned to live with those.

Karen

Yeah. And you get, you make an amazing point, which is that. There are sometimes strategies that we know about, and we've studied and we've thought about, and we've tried to make better through devices, through therapies, certain things that we know, but then there's the informal things that we don't know, that work maybe on an individual basis. Right. You know, how are you going to get around a certain just a certain situation. And in this, I guess in your experience here with your little aunt, you know, how much language she was able to acquire and use and write. Yes, yes. And and make herself and her needs known to you. So that's interesting. Umm, yeah.

Hanne

Yeah, I think it's something that's very important and we should really talk about cause other things here are also like, like her she was in an environment where no one was deaf, or no one was from the deaf community. No one spoke sign language. Neither did she. And that can happen to a little baby too. A little baby can be born in a family who is not familiar with the deaf community and then and did not expect to have a child who was hearing loss and I think some parents who might be listening to this or or people who are going to become parents soon. Might find it very helpful to hear.

Karen

Well, this is an important part about early hearing screening programs, which I think is something over the past few decades that we've really understood to be absolutely crucial because you can't see a hearing loss and a baby, it can be very hard to know .And you can hear in in these episodes the team members will tell you in some cases how their families identified their hearing loss when they were babies, some younger, some a little bit older and and in many different situations. But if you have a program where every baby, newborn, day one, is tested in some way for hearing loss, then at least we know who has a hearing loss

now. Some of our tests now we can use to predict who is at risk for having a hearing loss in childhood and even later into adulthood, through genetics and through, you know, some testing of a particular virus, for example, cytomegalovirus. So, that really gives us a chance to know and to provide support from the very, very beginning. What you're saying is it's really about language we really need for all children to have access to language because that's how we connect to each other. So you know.

Hanne

Yeah.

Karen

95%, I think that's the stat that we generally quote is that 95% of children with hearing loss don't have in their immediate family another person or their parents are not individuals with hearing loss. So it can be a very new thing to face by parents.

They weren't thinking about it. And so the incidence of hearing loss in the general population is considered to be about one to three in 1000 babies. So it's not an insignificant number of babies that will have hearing loss or who will be at risk for hearing loss. So it's so important to identify them early so that we can help as soon as possible and that is important times in development.

Hanne

Yeah.

Hanne

Mm-hmm. Yeah. That was actually one of the things that surprised me most, like, right in the beginning when I did my PhD and I was looking through the clinical charts, how often the hearing loss was diagnosed quite late. Because sometimes the infant screne, they failed it, but parents might not have followed up or it was a bit inconclusive. So it happened quiet frequently, actually, that that children were only diagnosed late when they started struggling in school or were late with language development. Because as you said, language is one of the very important aspects here. Because hearing does affect language. But then there's other cases that are also hearing loss, but people think less about is when it's in one ear and

through their one good hearing ear they are able to acquire language and then it's only even later that the hearing loss in that ear is diagnosed.

There were some stories of parents who told me they only realized, for example, their child had hearing loss when they started using earphones, and the girl kept saying "yeah, my earphones broken in my left ear, my left earphones broken, but then it turned out she didn't have any hearing there. Or they're playing a game like charade. And then the parents realized they didn't understand anything when they were whispering in one year.

Karen

That comes up actually in the podcast very clearly because there's a lot of diversity in this team. So we have one university student, she's at the University of British Columbia who you'll hear from has a single sided deafness. From as long as she can remember and. She describes her hearing difficulties in some very similar ways to some other team members who have, for example, bilateral profound loss and use cochlear implants, but that residual hearing, one of the biggest differences, which is interesting is you're going to hear them talk about turning sound off. Because of the fatigue, it's the first episode where you know our first discussion, where they really talk about the fatigue in listening and communicating because they put so much effort into it and they do beautifully. I mean, it's it, their language is great. They're so successful and interesting people. And, but the fatigue of listening all day is there. So the one user with two cochlear implants can turn those devices off. Whereas yeah, somebody with single sided deafness that, you know that's not going to be possible. That hearing is always there in the one ear. And so just the struggle to listen amidst having no hearing on one side. She does some other things to try to like, you know, just relax at the end of the day and we have the same thing. There's one of the implant users has some good hearing on the non-implanted side. So where's a hearing aid on that side along with the cochlear implant on the other side, we call that bimodal hearing. And so again, in that case, she can turn off the devices, but she still has, like a little bit of hearing that is remaining even when the devices are off. So what you're going to hear is something I thought fascinating is they actually love to just play like music super loud.

The way they talk about it makes me think that it's just one input, so they don't really need to interact with it. They're not expected to comprehend and then respond and then have a back and forth like you do with a conversation. They're just immersed in music. One sound at a time. It doesn't have to be understood as one thing or another thing, and they just, like, let it kind of come in and they say that's kind of relaxing, which is also an important part about music, which I know we want to talk about a little bit more later on.

Yeah so and I think listeners here, like for us, with normal hearing, it's a little bit hard to imagine what it is like to only have one hearing ear. I don't know, like every time I talk about my PhD project, which is on single sided deafness, a lot of people ask me like, yeah, but is it really that important? And I think that is because we just have two ears, so we don't really realize until I start explaining, how we know especially hearing is important. So actually what I brought here with me today is a little bit of an experiment. That's the PhD student in me that wanted to show this.

So what I did is I took the music that you talked about the doctor Pepsin made right, our introduction music. So play it twice. So first, because I think most of our listeners now will be like using earphones or headphones or will be in a car where there's like a stereo sound. So I'll play it in its original mode, what is intended to do, in the stereo sound. And then I'll repeat the same music. But what I did is I removed the complete right channel.

Karen

I love it. So it's gonna be first the original version and then simulated single sided deafness.

Karen

Yeah. The other thing that I think people can do is just put in one ear plug. Like you know those little foam ear plugs. You can put it into one ear and go out and about your day and see how easy or, you know, actually how challenging it is to just navigate through the world and into your normal conversations in in typical situations when you only have one ear. And that's a very modest attenuation of sound when we use an ear plug. So it gives a very small appreciation of what it would be like if you really had almost no access to sound on one side.

Hanne

Uh-hm, yeah, I think another example here is, you know, I'm from Belgium. So what I do a lot is FaceTime my family and I always use my Airpods and sometimes I'm talking to them and it's like, what happened? It sounds like it's away from where I wanted to hear the sound, it's not centered. It's like on one side. And then I realized one of my AirPods airports is disconnected.

Karen

Yeah. And I think it also shows you the benefit of having 2. So even if we're not perfect at restoring spatial hearing with two devices and that's a discussion we have with Ruth Litovsky, it's like the very first episode we have.

Hanne

Yes. Very first episode, yeah.

Karen

So it's not perfect what we do with two devices, but the benefit of having two rather than one is still there because it's just an added input on the one side, which really does help in certain situations.

Hanne

Yes, and the question that now a lot of people ask is should we give that implant in the deaf ear of children with SSD as well. So they have those two sides?

Karen

Ohh this is a you know, it's such an interesting group of children. Because I think our work and is just a part of decades of other study with children who have unilateral loss and this single sided deafness really is a particular group of children who have normal hearing on one side and very little access to sound on the other side. And so many of our studies show how much they're struggling. And so it's not surprising when we hear May. In the podcast talk about, you know, her difficulties listening with only one ear. So we know that this comes across from academics and justice, you know, struggles, listening and and noise problems with sound localization academics are affected. Language is affected in terms of the developmental trajectory and the rate of language acquisition. All of these things, even you know self esteem can be affected.

So we know this and we want to help very badly. We do want to try. And that's where we get into this question of, well, what can we do. So traditionally the these hearing aids and our

technology and cochlear implants and that technology has been used to try to get access to the auditory system on one side and give the amount of stimulation that that side needs so that sound can get to the brain and get processed. So the question with single sided deafness is hard because if you put a hearing aid in, there's very little residual hearing to work with in in this particular type of asymmetric hearing loss or unilateral hearing loss. And so a hearing aid may be very, you know, it just may not work and it might just be noisy. And and difficult to use. So people have put on things like bone conduction devices as a way of creating a microphone on the side of the deaf side, so that information is sent directly now to the hearing cochlea. And that's just another way of using the normal hearing year to get sound from both sides, so we have other technology that just has a microphone that will then you know, send information over to the other ear. But then you have to wear a device in the normal hearing ear which some children don't like very much. And you know you don't want to occlude or cover any of that normal hearing up. So there's those are available, but they were not, you know always accepted.

And so then, you know, the idea of a cochlear implant is really attractive. Right. Because we know the implant can stimulate if there's an auditory nerve on the on the impaired side, the question is, you know, the implant works so differently than normal hearing does. And so how do you connect those two different inputs? That we had some, you know, couple of different reasons where we thought there was hope of benefit in children with single sided deafness for cochlear implants.

The first thing is that there were a number of children, and you'll hear Mariam talk about this In the podcast, who could combine a hearing aid on one side with a cochlear implant on the other? Yeah, successfully. So and that, that already was pretty remarkable to us that yeah, so you can have acoustic hearing on one side, electric hearing through a cochlear implant on the other and still get benefit. That's pretty amazing. And then we heard you know that in adults who had single sided deafness, they were really experiencing some benefits of having a cochlear implant. It may be, as we learn more about those adults and as more adults like that will get cochlear implants, that some of that has to do with motivation around tinnitus. So if you lose hearing in one ear, there can be this annoying noise that's generated as you know, just part of the hearing loss pathology. And so that noise that tinnitus that we can be ringing in the ear, it could be buzzing, it could be all can really be just very distracting and affect to how you listen, even though you've got 1 normal hearing here, so it's above and beyond what we're talking about with problems with spatial hearing. So in those cases, having a cochlear implant actually seems to be quite helpful, just even to over shadow the tinnitus itself. And so there are other adults that do seem to benefit from cochlear implants with single sided deafness. And so that gave us some hope for using it in children. And these are relatively early days of this intervention in children with single sided deafness, and there

are so many different kinds of single sided deafness. Right? So many different reasons that a child might have hearing loss in one year and you know it could start right away and at birth it could be. You know that there's no nerve, in which case a cochlear implant won't work. There's no hearing nerve to stimulate them. That's not a cochlear implant candidate. But you know other reasons. Like this virus. Say the Megalovirus. As you know, if the children have had this congenitally and it will, it can affect one ear and not the other or one year. We should think about it as affecting one year before it has a chance to affect the other year. Because there is this risk that there's going to be deterioration appearing on the other side.

So there's that and there can be differences in the shape of the cochlea on one side, there can be genetics that are the reason. There can be an older, you know, as children get older, they could have normal hearing in both ears, but they could have trauma. In fact, my own cousin. That's that was the case after. He fell as a three-year old and you know, he unfortunately had a fracture that went right through the cochlea. And so that, you know, to have that becomes a reason for the deafness on one side. So we really want to help these children and the cochlear implant has some promise, but there's also the reality of how it is integrating with the normal hearing ear, which you know, is variable and the outcomes we see are variable. And that's what we're learning, why do we get benefits in some areas and not others? And why do some children like their devices and others don't?

Hanne

Yeah, that is a very good question. And unfortunately, surgeons cannot determine in advance when the little baby comes, whether this will be one that will benefit or will not. And there is a lot of things that we still are still left to discover. But that's why we have research and Dr. Gordon is doing a very beautiful job here. Is an amazing supervisor and there's a lot of research going on that looks at. This one of the things that I wanted to talk to I talk about as well. So we have mentioned it a couple of Times Now. It's cytomegalovirus because, well, that's the that, the little virus that has been mentioned here CMV and I think a lot of listeners might not know what we're talking about, but it is actually one of the most common reasons of hearing loss in the Western part of the world, like North America or Europe, and it is actually a pretty common cold. And if a mom gets it during the first month of pregnancy, then this can cause hearing loss among a few other issues.

Karen

To the baby, yeah.

And yeah, I think people are not aware of how frequently this can happen and there's actually nothing that we can do about it right now.

Karen

Well, I think knowing about it is an important part. I think you know, when I started audiology, we were aware that this virus could have. Pretty devastating impacts on development and on hearing. So we saw babies that we now call symptomatic at birth for cytomegalovirus where, you know, they were quite ill and we were following them. And so there were. A number of clear impacts on how the child's developing, including hearing loss, what we've learned, though, is that there can be asymptomatic cases. So the baby looks, well, completely fine, but the virus is there and can be in the ear, can be, you know, active elsewhere. For example in the brain. And the effects are seen maybe later. So you know in the ear, when I say the ear, it can be affecting the hearing part of the inner ear, but also the balance parts of the inner ear. And so this is what has created an important objective or aim for our province is to identify newborns who have this virus. And we would like to understand, you know how this virus has affected them from the get go and some of them already have hearing loss. Some of them don't. But they are at risk for having hearing loss, so we really want to follow them. And there are some, you know, potential treatments. There are antiviral medications that might help. That's being studied. You know, it would be amazing if one day we could have of a vaccine that protect, you know, us all from this virus because obviously we're better able to handle it when we're adults than, you know, when we have a developing fetus or newborn right? So that's what I hope for in the future, but we are learning a lot more about this virus.

Hanne

Yeah, it would be amazing if there would be a vaccine because that's one of the reasons that causes, like rubella, for example, are not that common anymore because for rubella, we do have a vaccine right now. So hopefully there is a research team who is close to a breakthrough with the vaccine.

Karen

And that's a good point around meningitis too, right? That that when we started in audiology, one of you know, there was a significant number of children who after getting this, it could

be a bacteria, it can be a virus for meningitis, but it's an infectious cause for hearing loss and there are vaccines not for every possible form of meningitis, but for some of the main ones. And we saw dramatic decrease in the numbers of children who get meningitis and therefore hearing loss as a sequelae or a, you know, consequence of your of meningitis.

Hanne

The vaccines are something that are actually quite important here and especially because, you know, these infections often happen in the families who do not have any relation to deafness. And they don't have the sign language and the community yet. Because in these cases they are not able to teach their babies the sign language yet. And as you mentioned, one of the most important things here is language, because language is not only important for hearing, but there's a lot of networks going on in the brain that reach beyond the auditory system, and I think that's a lot of your work goes into that as well, if you're not able to teach your children any language, how would that affect them?

Karen

Yeah, I think that so much of what we are as humans is this idea to think and communicate and interact. So it's true, language learning in the first years of life is just a phenomenal thing to watch, in whatever mode as you say. You know, whether it's a spoken language, and there are so many different spoken languages in the world and sign languages, and there's many different sign languages in the world. But for any baby hearing, you know 1 dominant language or being exposed visually to 1 dominant kind of sign language, It is such a complex processing of what constitutes meaning within all of that ongoing, you know, stream of language. So if we think about the oral language that we're using now in English, you have to be able to break it up. Into its pieces. So what's even a word? I mean, Hannah, you speak so many different languages. I only speak one language. But you know, so first, just understanding what's a word and what is this word, there's so many parts of sound that go into having a word that is, you know, ball versus bat. You know there's there are different sound structures that create that and that to associate each of those sounds altogether as a word to something, and to use it over and over and over again. So you know this idea that babies will hear a particular word, hundreds of thousands of times, and then, you know, understand it as an entity and with meaning, and then be able to articulate it themselves is a nominal phenomenal thing. And then to think about. Well, could you do that in another language as well?

Yeah, yeah, I. It's so cool. In my first year of the PhD, I had to take a few courses and for one of them, I actually wrote an essay on language learning. And what I found really cool is like how you know every newborn baby, they call him the citizens of the world. Cause any baby, doesn't matter where it is born, can learn any language as a native can. You can put a baby from Toronto and all the way to India and it will learn Hindi like a native, but do this with a 20 year old or a 30 year old and you'll get an accent, like my accent right now.

Karen

Exactly. And there's going to be a time that that happens where the brain is just ready to take it all as it is. I love that expression. The baby is a citizen of the world, the baby's job is just to learn. You know, what voice is coming at them most often. So familiar voices they can tell before, you know right away, before even the understanding they know "Oh I've heard that, that's Mummy, you know. And that's a different person. So our voices carry meaning. Just for the identity of who we are and then and babies can pick that up and then they get the meaning of it. And then as you say, then, there's beautiful ways that the brain becomes efficient. Because we can't just be taking in information. Ultimately we grow and we have to process and understand, respond to that information. So we can't just be intake processing all the time. And so as that efficiency comes in, as complex as the processing becomes more nuanced and complex, then we start to see what we lose. We have to we lose some of that global citizenship as as we age.

Hanne

Yes.

Karen

That we, you know, so the babies will prefer the language that they're expecting because that's the one that they're exposed to and and they are developing meaning for and you can actually see those complex responses to. What's understood versus not in the brain and babies and that's what we're talking about with language networks.

And this highlights again how important it is to give these children this access to sound very early on, especially the children with the bilateral deafness, so they can start acquiring language from a very young age. And I think one of the things that I found most fascinating during my time here at the lab so far is hearing these children who. Had bilateral deafness from where it's got the bilateral coherent implants. And then you talk with them. And if you don't see their devices, you wouldn't know that they had deafness, they speak like normal hearing children do. And it's only when they start taking off their devices that little by little the speech starts degrading, and that's when you start to realize ohh these children have hearing loss. And I think that's such a beautiful thing to see how they were able to acquire this language like the native even though they didn't have hearing.

Karen

And that self monitoring is really important. You're right. If we don't have a way of monitoring what we're saying, yeah, can change. And so if anyone goes on to listen to this upcoming episode, you're going to hear different articulation patterns by different people depending on the type of hearing loss they have. And this has to do with different degrees of access to sound at different times in life, particularly hard for individuals who had limited access in early stages, while language and language formation, production, articulation, all of that is happening to get that right later on. So we know again that there are these like sensitive periods for language understanding as well as production. So that's, you know, if you try to change your accent now that's going to be harder.

Hanne

Yes. Believe me, I've tried, I've tried. I think it's just a beauty of my my background.

Karen

I don't think that. Yeah, I mean, it's really not. When we hear English being spoken in many different accents, that's, you know, it's what we're used to in Toronto. That's like, everybody has a different accent and I and I can relate to that because I also came from England as a child.

Yeah, I remember that.

Karen

And very few people could understand me, and it was a highly motivating reason. You try to form the Canadian sounds because even if you have normal hearing. You're expecting a certain way for the language your native language to be spoken. So even an English speaker going into different places can have difficulties when the accent, the rhythm and the you know, the valve formation is different. So you know having, I mean, we're used to in our program hearing English in so many different accents that you know it becomes, Yeah, you just become more of an expert at just hearing the word out the expected, you know, exact rhythm and rate of that vowel or the whatever it is that creates the different accent.

Hanne

Yeah. So I follow up question that I have for you, how old were you when you moved to Canada?

Karen

Still very young young.

Hanne

But other friends here in Toronto, and she's originally from Germany. And she moved when she was 14 and. Well, you you'd expect that you would have some kind of German accent in there, which she doesn't. And she told me. Yeah. Well, I mean, you don't want to sound different in high school because I'm in different equals getting bullied. And I didn't want that. So it was a very strong motivation to learn those Canadian sounds. So even as young adults, there's still some plasticity there to, to, to change it or adapt more easily than I am doing now.

Karen

Well, I think this is also so interesting around, you know, what part of plasticity, what component of that is really dictated by limitations in the system, you know, just the the primary system. And we're talking about hearing, so in the primary auditory system, how much of that can be modified by cognitive factors. Just trying more or different, you know? So, this is a part of learning, right. So what's the difference between the ability to change and learn? And that's where we are at in our studies now, is that there are going to be some parts that we can affect by learning cognitive strategies to try to, you know, get different parts of learning accomplished language learning. Academics, you know, these kinds of things, even, you know, we're thinking about spatial hearing even when you don't have, you know, the right cues, could you use other behavioral means, other kinds of cues in the environment, visual cues, etc, to help with that overall learning. And that may be quite different than trying to change the auditory system itself, right? So we're probably going to need some, you know, really important input to the primary system and very specific periods by which we can then use other cognitive means to pull and change and support. But if we miss it completely and we never have any sound coming into the auditory system that you know, the system can change such and the loss of important times in language learning, we may not be able to ever get back even, you know, no matter how much we really try. So this is a so we need always this, you know to identify hearing loss in children. That you know, as soon as it happens, if possible or as soon as you know, and whether that is as newborn babies or when when it comes, maybe a little later on in life for whatever reason. And then to support that through the devices we have, get the auditory pathways functioning and then support that by other language techniques, and then think about the whole child. Within the family and support that you know by trying to provide the structures and resources and so forth that are required there.

Hanne

Mm-hmm. Yeah. And then so we've now been talking a lot about language, but there's something else that's very related to sound. And the auditory system. And it's also very important in our daily life, especially in this time and age, is music. And we've already hinted to it, and we want to talk about it. And there's already been an episode where this has been discussed. I think it's season 1 or 2 with Doctor Basquez, I think. Yeah. What about music and how can we help children who have hearing loss? Whatever the the degree of hearing loss and how can we help them with music experience. And is music therapy is something that we can look at because there is also other studies going on about music therapy or is the cochlear care implant helping them with music. What are your insights here?

Karen

You know what it is fascinating for me to be in this auditory community. Because many people come to it from their love of music. So there are some incredible musicians in this community. I'm not one of them. I love music. I'm an engager in music. I do think that there's something important about language and connecting to other people and you know I. I'm an oral spoken language person, so that's how I connect with people and music seems to be a universal experience. So even you know, if you have no access to sound, even the rhythm for vibrations, somebody can get that feeling of music. So music and the emotion that music carries, with meaning, you know, the emotion becomes meaning, and there's also, you know, there are there is language that's communicated through songs and through melodies and so forth. Those become meaningful and it and music naturally happens in every culture all over the world, and music itself can have nuances or you know depending where you are in the world. It i's fascinating to me. It's not my area, but it is fascinating to me. And so it's not surprising that some people are asking, well, if we're giving back sound to people with hearing loss, does that sound include music? And that is so important and you can hear it in the podcast, like I said, you know the. All of the implant users and the siblings also say that their siblings really engage with music consistently, so there's something about music that really we all want to be part of. Except for those who are, you know, we've learned a little bit about from collaborations with, for example, Isabel Peretz in Montreal on people who are amusic, a have a musea, that's the better way where, you know, they hear music, the way that it's coming into their auditory systems, or the way that it's being processed, maybe by the auditory system, is abnormal, and so it becomes something that's not enjoyable. It's there's too much, just as a lay term, noisy to really enjoy so.

This is something we really want to understand, is what does it mean to have music processed by this device, the cochlear implant, which really was not designed to do that. It was more focused on trying to pull out the. Speech sounds. Uh. In that are common in in many different languages. Within this you know the, what our vocal cords can actually produce, and you know to do that quickly over time. But music is actually quite a different experience and it's processed in some ways differently by the auditory system. And so that the information that you need actually needs to be a lot more precise for understanding musical components. So for example, the differences between you know, something that is within a particular key or not, so if it's mismatched or you know, just listening for things that you know get higher in pitch within the same key versus not. These subtleties, or distinguishing between different lines of different instruments that are playing together or that kind of thing.

So there have been a number of different people who've worked on that that we've learned from. I think we found interestingly that the emotion that's carried in music can be carried in different parts of music. So this test that Isabelle Peretz developed where you're asking children, you know, is this happy or sad music? It's fascinating to see that many of the children using cochlear implant can do that. They just use a different cue. They use the timing and the rhythm of music rather than the mode or the major minor keys to do that, so it's so it's a different, completely different way of listening to music. But it still works.

Hanne

Yeah, it's fascinating. It actually makes me wonder, like, what about the tonal languages like languages like Chinese or Vietnamese, who are a lot about intonation, is the cochlear implant a little bit more difficult there for language than it is for language like English.

Karen

Such an important question, Hanne, and so intuitive and the short answer is yes. Yes, tonal languages have more difficulty because again, the subtlety of needing to understand switching in pitch, very subtle switches or or changes up or down, or that again, because I'm not a native speaker of Mandarin for example, I don't hear them either, but. But you know how we can give a Mandarin, you know, a child and a Mandarin speaking family with a cochlear implant acess to those cues is really important. And then how we can again support that learning? Even if there's, you know, pretty limited information there. But there's still work to be done because those tonal languages are harder to get some of those, those subtle nuances and frequency change.

Hanne

Yeah, I can imagine. And I know, like words, meanings change a lot depending on the donation, so it might be a lot harder for these children to understand.

Karen

Yeah, exactly.

And now I'm also wondering about being bilingual because as you said in Toronto, a lot of families are international and there's a lot of bilingualism. Also, in the children that I've been testing, I think at least half of them are from bilingual families. And a lot of the language I've heard is also Chinese and and their English is amazing. And I'm wondering if if children who are bilingually raised, if this might also affect.

Karen

Yeah, I think people would be surprised to hear how many different languages are spoken in the families that we follow in our book. It's, you know, I think the last count was well over 20.

Hanne

Yeah. Oh yes, I believe that.

Karen

And you know, if we put in different dialects and so forth, there's going to be many, many, many more. It's fascinating and you know, when I started in the cochlear implant program, like billions of years ago, the advice was no stick with one language. So just English, and we're not going to give, we're not going to expose children to anything other than English. And that's changed over time. It really has. Really also out of necessity. So most of the children who are in oral language learning programs, and that's really the majority of our children that we see, are developing oral spoken language and they're in class listening. It can be, you know, different languages, so there are French immersion programs, for example, but the majority really are hearing English in the classroom. So English is going to be a big part here in Ontario, not in all. You know, there are again, more, more francophone areas and there are French immersion programs. Uh, but when they go home, they're going to hear just different language, just the reality. And you can see that children can do both they and it's incredible to watch these children who would have had, you know, very significant language delays without cochlear implants and without identification of their hearing loss, etc. Learning 2 spoken languages perect.

Hanne

Or more or more yeah.

Karen

Or more yeah.

Hanne

No, I think it's very fascinating and I think it's a field. It's very important. I hope a lot of people will be listening to these episodes and especially the next ones where you will be talking to all these amazing young professionals who have their experiences to share and then maybe people can start to understand a little bit more because a lot of that I have heard from parents of the children that I've been working with. Is that the school sometimes doesn't really realize their struggles, and the teacher doesn't really realize that the children have challenges that they have to overcome. Because it is not that obvious, right? Because they have their hearing devices. And so I think, well, I hope that with the next few episodes that maybe this podcast can raise some awareness.

Karen

Well, I think you're going to learn also what it's like to be a child with hearing loss in the classroom. Any of these. I think in all of these cases, they're the only one with a hearing loss in the classroom, and so there's some questions about do they want the other children to know about their hearing loss? So if they have support that comes in in an early class you know, in an early, elementary classroom, they may not want to be called down to the office to see their support itinerant teacher through the, you know, the PA system so everybody knows they're being called to the office. Right. There's a little bit of practical advice that they share and also their those personal experiences of like well, hang on I want to be able to control like how much low and then when am I being taken out of class and I think you know they're talking about their memories of what it was like to be a child and also how they realize as adults, later young adults, but adults later, how much that helped was important to them when they were little and how much that that created opportunities for them going. But yeah, those are real experiences of what it's like to. Just try to navigate through with the hearing loss and then they talk about you know what it was like to be in high school and some of the nuances there and navigating, you know, high school situations, social situations, and they do talk about all of these things and the effort that it takes. And how they managed to get through. And they're just real superstars in the sense that they can just recall and express their experiences so well and it was just such a wonderful experience for me. It was really an honor to have these discussions with them because they really taught me so much more than what I knew working with these families over so many years, and I think some of that is because this is the first time that we've had an opportunity to watch somebody with hearing

loss, you know, significant severe to profound hearing loss grow up from young childhood into adolescence to young adulthood with a cochlear implant. Because these things were have only been around for 30 years. So these are, you know. Unique experiences, and they're telling us about it. It's just amazing to hear.

Hanne

Yeah. And do you think that the children who are in school now, like in primary school or? In high school that there's a bit more awareness there about like hearing loss and cochlear implants because of social media or TV shows or.

Karen

I don't know. I don't know.

Hanne

One example that just came to my heads is, like one of the that I I tested, she told me, like, oh, you know what, like in the bachelor, one of the bachelorettes now has a cochlear implant. And all my friends saw it. And so I think it's. Come getting there more. I know one of the the ministers in Belgium now has cochlear implants as well. Like this it is coming like.

Karen

In yes.

Hanne

No and and.

Karen

Yep. I always tell people, you know, when we first started, if there was a child that I saw out and out and about, you know, downtown Toronto with the cochlear implant, if I didn't know that child, they were for sure from out town. Yeah, because I, you know, we had only so many children who would receive cochlear implants, and we followed them so carefully, you know, carefully and closely. And we just knew them so well. Now, that's not the case just because you know, there have just been hundreds and hundreds of children who have received cochlear implants through this program over the past 2 ½, almost 3 decades. And so this is a growing community and definitely we've learned a lot more about how implants work. We've expanded, as we talked about you know from children's bilaterally profound in both ears that received only one device and we are giving bilateral implants and we moved on to children with asymmetric hearing including children with single sided deafness. So there's there's a lot a lot of expansion and change in candidacy and some changes that have been important in terms of the technology itself. So this will continue to evolve as healthcare always does, and as our learning and understanding and our research continue to find ways to improve.

Hanne

OK. Well, I think that is a very beautiful conclusion for our episode here today. And I am very excited about the next year episodes and I hope I really hope our listeners are too and that they stay tuned for the next few episodes. And then I really want to thank you here for your time today.

Karen

Thank you for putting this together, Hannah. It's lovely.

Hanne

Well. With pleasure, with pleasure.

Karen

Always fun to chat with you.

[music]

Karen

Thank you for listening to this episode of the Here Hear Podcast Season 4. I hope you enjoyed this conversation. I want to give a shout out again to the here here podcast team. Nimrat Chani, Mei Wang, Maryam Othman, Sofia Olaizola, Maria Khan, Annika Gasee, as well as my colleagues that are involved. Laura Carinci, an audiologist here at the hospital for Sick Children, Dr. Sharon Cushing and Dr. Blake Papson also. I hope you enjoy this music which was performed and composed by Dr. Blake Popson. Thanks for listening.