Season 2, Episode 2: Hear Here Team Transcript

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Karen Gordon: For this next episode, in our season 2, we had the chance to sit down with our Here Hear podcast team. These are wonderful members of our lab, and I, I just want to recognize them now. We call them our Lab ambassadors. A couple of them agreed to come on as our guests for the podcast. There's Sofia Olaizola who is a cochlear implant user -has been since she was very young. She tells us that she was 11 months. You know her early memories of mapping and what it's been like for her to grow up with the cochlear implant. And then Maria Khan, who is a sibling of a cochlear implant user - her brother, received a device, also as a young child. And she brings to us the insights from living with somebody growing up with a cochlear implant. I just want to tell you, this team of young people have taught me a lot about, not just growing up with a cochlear implant, but just being young people in the world. They are similar ages to my own children, and they have a lot of the same struggles. What do I want to do with my life? Who am I? Who do I want to be? How do I want to make an impact?

Introductions to the Podcast Team

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Karen Gordon: It is wonderful to have you guys here. I'm going to describe you in general as students who are involved in Archie's Cochlear implant Lab. I think people will get to know you a little bit more through this podcast. So let's start with, why did you want to get involved in Archie's Cochlear Implant Lab?

Maria Khan: Alright, cool. I am not a CI user, a cochlear implant user, but my brother is. So I grew up with somebody who is hard of hearing, he has CIs, this is my reality. Scrolling through the Internet I'm like, wait, what if I get involved in CI research?, I could be giving back, like, you know, the people and the cause that helped my brother get his CI's. I remember going down the halls where the lab is to see all the farm animals on the wall.

Karen Gordon: You had already like this connection to the physical place because you came with your brother for appointments. It gave you a little connection there.

What about you, Sofia?

Sofia Olaizola: So I am a CI user, I have been since I was eleven months old. Archie's Cochlear Implant Lab has kind of been a lifetime thing for me. I've been going to SickKids since before I can even remember. I've always been really interested in the research they've done on a personal side, because I also think that in research it's important, to have, to factor in patient experiences. Researchers are always talking about what's the gap in the literature, they're always trying to figure out, ok , what is really important to know, but it's like patients are living the gap. They know what is, like, the most important things to be looking for and improving. My whole life I always thought okay, I could be really useful in that way. And so, I've always wanted to just be a part of cochlear implant research because of that reason.

Karen Gordon: When you reached out. I thought, this is such an amazing opportunity to get a perspective on our research that is just invaluable. And I've told you all so many times how much I appreciate you getting involved.

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Getting Involved with CI Research and Role of Audiology

Karen Gordon: I really appreciate also your your comments about research. What do you want to say to people when they think about cochlear implant research?

Sofia Olaizola: I mean the Cochlear implant technology is out there, right? But that's not just it like with all technology, there's upgrades, there's flaws. There's um things that need that all it can always be better. for instance, the way the technology has changed just in my lifetime is ridiculous. So, I can only imagine how much more it can change in another twenty years. Research makes these kinds of things happen. The first piece of technology I owned in terms of cochlear implants was a cool contraption of like five different components. It was a giant processor that um was really heavy, and it needed to be uh put into like pockets in t-shirts. So we had to sew pockets into each t-shirt to put that processor inside, and that was attached to like a wire that would come out of like the collar of your shirt, and then it would go onto this earpiece, and then the earpiece was attached to like the magnet. And then now, the processor that I have is literally the size of like a toonie. It's a small little circle that just goes on my head, and it's even bluetooth-powered. The cochlear can just connect to my phone and that's it, and so it's just mind-boggling how advanced things became in such a short amount of time. This technology has been able to keep up with, like the general population technology, like, for instance, when the AirPods came out and everyone was using AirPods, that was around the same time, when we were able to use a little bluetooth clip, to listen to music from our phones, and be wireless as well like with everyone else.

There's always areas for improvement like we still don’t know why cochlear implant users are not able to achieve binaural hearing when they have two cochlears, That's still something we don't know. Like sound localization that's still something that's a problem. I've spoken to a lot of users. there's always room for improvement, and even there's a huge one that I know some labs are looking into, which is hearing fatigue and how cochlear implants can affect your cognition. And, um, just like looking at the connection between cognition and wearing the technology because it's a lot of work for your brain to have to like hear all the time. It's not a natural process that our brain like we're born with. It's something that we learned. It's an acquired thing that we had to actually teach ourselves through speech therapy through auditory therapy. It's like a skill, you know. It's not so much like a natural thing like people who are born with good ears.

Karen Gordon: I think that that part is something that we're learning just takes a lot of effort. And that's something that we, with the people who are doing the research with normal hearing, just can't really appreciate the same way that that you can, So maybe tell me, Sofia, a little bit more about how you feel that fatigue.

Sofia Olaizola: This particular thing is that we only wear our devices when needed. For example, I'm wearing it right now, because I'm having a conversation with someone. But as soon as this call is done, I'm probably going to take it off if I'm not having to talk to anyone. Like when I'm at home, I generally have it off. I have it on when i'm out in public, because I need to be aware of my surroundings, and like cars and stuff like that. But, for instance, when I'm at school, like at the library, I'll have it off while I'm studying, because I find it really difficult to study and work at the same time as having it on. Hearing is so much work that I can't like dedicate so much of my brain energy to hearing and working at the same time, like I have to kind of segment it. For example, when I'm writing, exams or tests, it's impossible for me to write them wearing with wearing my CI, because, I don't know what it is, but the second I take it off, I'm able to concentrate and focus on my work so much easier. It doesn't even matter if the room is quiet, like even the quiet sounds are a lot of work like the wind, or anything like that. Really, what it feels like is like at the end of the night, when you come home from a long day, and you just take it off. It just feels like you can just reach relaxation. Like you're not able to relax until that moment when you take it off and you're just in peace and quiet.

Karen Gordon: Maybe what you're talking about is just giving whatever rest you need. Um, and then it also allows you to move into a new phase from work to home to whatever. But the other part is, you know, divided attention. You're trying to keep the room quiet, as you say, and like any little distracting sound, will be an issue, so I can appreciate the fact that this takes you away from the task at hand.

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Karen Gordon: You know we've looked at how the brain responds to the subtle details in the cochlear implant stimulation. We've talked about limitations in the device. But at the end of the day their biggest complaint is I'm just tired at the end of the day. Sofia says at the end of the day I come home. I take off my devices, and I'm just so happy to do that. And it, it reminded me of like coming home at the end of the day and putting my feet up.

Blake Papsin: Fascinating, I, you know, a long time ago there was a lecture that I used to give, and I would talk about how men wear ties so they can fit in with the rest of the world, and how starlings fly with the group and how they get their cues about where they're supposed to be. And and I used to say, you know, like you want to go for coffee. Yeah, sure. And the deaf person is you want to go for coffee? Yeah, sure And that what happens in those two seconds is really is really exhausting, because the brain of the recipient is, “what? What? What? Co. Coffee? Coffee? Right? Yeah, yeah, I do”. And that's exhausting when you do that 60 million times a day, and I do know now that I wear a hearing aids when you come home and you take them out. Being deaf is, is exhausting, and it's exhausting on your relationships. Not just me, it's exhausting on every one of my family. I have the excuse of being a crabby old guy so people don't question that. They just think it's my age. But it's also my exhaustion from trying to figure out what everybody's saying all the time. Really? This is the best we can do? With time delayed field, no timing cues, that's the best we can do? Are you kidding me? And the answer is, yes, this the the this this period of scientific revolution has come and it's had a long phase of iterative advancements, and it's over. We need something better, it's exhausting being deaf even with the cochlear implant.

Karen Gordon: So that is what resonates to me. From you, from Sofia, Maria and the other cochlear implant users who are engaged with us is, I want to help, we all want to help. We want to be part of this solution.

Sharon Cushing: We think about helping in terms of how can we make the technology better, but a and maybe we can also do a better job of telling them they're gonna be tired right? The number of times I've had teenagers come in, and they'll often come in, you know, because they have a newer history of headache. For example, you know, and I just, I say to them, of course you are. That is communication fatigue, and we put a label on it and tell them that this is universally experienced and absolutely of course you do. But we never told them that, but maybe we're going to tell them what they need to know about fatigue and what strategies they can use to make sure their tank is full. Making sure they have, like somewhat similar things, protein for breakfast, hydration, sleep all of those things that are going to make their tank full. I think we can help improve their lives without ever needing or having to rely on an advancement in technology.

Karen Gordon: I think also, provide peer support. Those experiences have to be shared, and, and some support might come from sharing.

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Karen Gordon: It's really important for us to hear about the fatigue that cochlear implant users and people with hearing loss are experiencing. At the same time, it's also important to recognize that these young people are making amazing contributions in academic pursuits and beyond.

Karen Gordon: So you were talking about your academics, taking exams that kind of thing. I wanted to ask both of you about what your academic goals are. So, you're both in university right now, and tell me a little bit about what you're doing, and also what you want to be doing with this university degree.

Maria Khan: So, going to my fourth year in the Health Sciences at the University of Waterloo with a minor in Addictions, Mental Health and Policy, and you're probably wondering if you're just in mental health and ask, why are you here in CI research? And I think for one, people can have multiple interests. Mental health is a big one of mine, but also auditory research is actually quite interesting too, because, like I said, I have a connection with my brother and as someone who lives with CI's it's my reality.

Sofia Olaizola: I'm I'm going into um my fourth year at the University of Toronto in Cognitive Science the program is fairly new, so what it does is, it combines five different areas of study: psychology, linguistics, anthropology, neuroscience, and philosophy. My specialization is language and cognition. I've always been very interested in language. So I um take a lot of courses about speech, language, disorders, and language, acquisition and things like that. After this year, I'm planning to do my Masters in Audiology, and then hopefully do a PhD and pursue research, but my ultimate goal is to be a clinician and a researcher.

Maria Khan: Goals I think I have for my future is either science or medical school. because again, with like CI implantation like It's just, I just find a very fascinating, but also audiology because the audiologist has a such like a pivotal part of our lives being an audiologist. You have a better understanding of like how to talk to a family about CIs as somebody as a family member with a CI.

Karen Gordon: Maria, just tell everybody who may not know what an audiologist is. What does an audiologist do? How were audiologists involved with your family?

Maria Khan: My general understanding is that audiologists will help the people of the family, this is how your child is hearing, and this is like what we can do to help like, improve, or make the hearing better.

Sofia Olaizola: What Maria said was right. Audiologists are there to listen to check in on your hearing to make sure that everything's going well. Um, they're kind of like the first person you go to if anything's going wrong like. If they can't deal with the problem themselves, they will direct you to who else. But more than that, I think that Maria touched on this, but audiologists are also kind of they're like a support system for the families with hearing loss. I think all families get for the most part get really attached to their audiologists. Um, especially at SickKids, because you're with the audiologists for eighteen years. The audiologist is there when the when the kids diagnosed, and when they get their CI turned on for the first time. I just recently found a home video from 20 years ago, when I got my CI turned on for the first time, and, like my audiologist was there, and it was like in 2001 , So it's all really sentimental. And when you actually go to the actual appointment, what they do - It's kind of like tuning your guitar, I would say. They tune your device. They put each frequency at like the um sound level. That's comfortable for you, and then they also test your hearing. They'll take you to sound booth and ask you to like re um. Listen to some words and noise outside of noise and quiet, um, just to see like where you're at.

Karen Gordon: Sofia, You um have been interested in language and learning, and you were talking about your interest in pursuing a master's degree in audiology, and that you were thinking that, being a clinician and a researcher would be a great future career, which I have to agree with (It's the best) as somebody who also is an audiologist and who does research.

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Blake Papsin: It continues to amaze me. How many people, how many audiologists come on to our team, and the reason why they started on their pathway one way or the other was because somebody they saw had this happened to them.

Sharon Cushing: You know I I love the connection that so many of the people we work with have with hearing impairment, and it really does, you know, drive them in very special ways. The other thing, though and and I say this about sort of my nieces and nephews, who are now considering clinical careers, they know they want to do something with humans. And and I'm sitting there going, "What about audiology?" And and the truth is is that not very many people have an auntie who says, what about audiology? It's not something that people know about in the same way that they might know about nursing or being a physician. And so I also think that that also comes into play. These individuals who are either touched with hearing loss or a family member with hearing loss know about it because they lived it. But perhaps there's more that we need to do to to demonstrate what an amazing career it can be as an audiologist.

Karen Gordon: Yeah, that's so true. I I came to audiology by chance. Before the interne there was no Google, and we were just going through books in the library of possible careers. I had been doing physics and acoustics. And this like, okay, there is an actual clinical program, a career that you can do that that really focuses on sound? That's the best. It's true that most people, even now, when I say, oh, "I'm an audiologist. Sorry! What? What is that? What is an audiologist?" So I do think we we need to do a better job, maybe, about explaining the role that audiologists have in supporting and treating hearing loss.

Blake Papsin: It's true. It's actually that. The audiologist role has actually become about talking about things like: "How do you date with hearing impairment? How do you introduce yourself to a group of new people who are your age who are teenagers like you or or young adults like you, who are going to immediately judge you? How do you adjust to the Internet?" And you go, "Well, how does that matter If you're deaf?" Give me a break. It matters plenty. It's amazing. So the audiologist of tomorrow and the young auditory scientists of tomorrow will have less to do with a fitting to target and more to do with adjustment of a of a sensory deficit and finding your place as a valuable human.

Karen Gordon: You know, you can say the same thing for many different careers now. We are in a technology age and there's going to be a lot of things that are done within lots of different professions that can be done automatically or through AI, or through a different technology software, etc. We're all asking ourselves as humans, "What's our role?" And of course, caring for other humans and advising other people and creating. I see this as an age of change.

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Sofia Olaizola: My parents when I was diagnosed, they had no idea. What it was. They didn't know if I was going to have to go to like a special school. They were going to have to learn sign language. If I was going to be able to do like singing, or dancing, or swimming, or anything like that, so it's really scary for families, luckily for my family, my parents had that and that was an audiologist at SickKids. Her name is Gina, and she has two cochlear implants, and she's been at SickKids since I was a baby. She was there when I was diagnosed when I was six months old, and my parents um had so many questions for her. But just seeing another woman with a cochlear implant, um, in a professional setting, working, as an audiologist, obviously very intelligent and successful woman, you know, being in the position that she is, and she's very um, she's a very good communicator. She speaks really well, and she's just like overall a really kind, amazing person. So, for my parents to see that, they were able to realize that being diagnosed deaf was not like the end for me. I mean, that sounds dramatic, but for a lot of parents like it's really scary, and it takes some time. And so, it just gave them a lot of hope for my future. And so, I think that, uh, it's really important to have more audiologists with cochlear implants, Also like Maria says, family members of cochlear implants - like people who can offer real support, like real hope for families. Because it's one thing to hear about other stories and it's another thing to actually see someone and see that they're living a successful life.

Karen Gordon: And that's why, again, I'm so happy to have you guys on on the team because you give me that reality check. Maria, it may be different a little bit different for you as a sibling to watch the process.

Maria Khan: At the time I knew that, oh, these are his ears. He needs to put these on so he can hear. So even like as a little girl like I had an understanding that he needs to wear these so he can hear. So growing up, we're learning how to you know, change the batteries. I had the responsibility. For example, if we're going in like a crowded space. I have to make sure that I can see him as he sometimes is confused. So gotta make sure he's by my side so he doesn't get lost, because if I were to call out to him he wouldn't be able to hear me that well. So that's just one thing.

Another thing- subtitles. To him, having subtitles makes the world of a difference to help hear what's on the TV. So we just we just chill on a couch to watch TV with our subtitles. Again, that's just like our normal.

And you also get like the understanding of, whole entire like like human being, They're not just deaf, they're more than just their um hearing loss. I try to advocate, for you know, for my brother. I think as the older sibling, I just find it important to advocate for my brother at times when I feel like they're like undermining who he is.

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Karen Gordon: This group of members in the lab, they love hanging out together. They didn't know each other before, and and I'm glad that this was an opportunity for them to connect. And I also am glad to take the time to tell them like how remarkable they are and how much they've accomplished. We're immensely proud of them, even though you know we're just such a small part in their lives. But I just am amazed at what they do. They're in university and they're getting social work degrees, and they're out into the world, and they're having their own children and coming back. We are in a unique part of this journey. We're seeing an evolution into adulthood of children implanted as babies.

Blake Papsin: they are amazing and kids are amazing. But the the problems -sometimes you forget because we're looking at at the through the lens of cochlear implantation and hearing restoration- we forget the greater problems in our society in general. It might be that the key to successful cochlear implantation has nothing to do with electrophysiology or surgical technique. It has to do with food.

Karen Gordon: Life is full of many different senses, many different needs. I think you know we we can advocate for people in our roles. But there's so much more that needs to be done for individuals and for on a societal level system, systemic levels. But hopefully, we're we're making some gains and we're acknowledging these issues even just by talking about it here.

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The BTS of Creating this Podcast

Karen Gordon: So let me turn the conversation to this podcast, because, we are together creating something which may help people understand a little bit more about cochlear implants. Um, some of them have never heard of cochlear implants before. Some of them are already well aware. Some of them are, maybe clinical people who work with people with hearing loss, whether they be teachers, audiologists, maybe even doctors who work with children with hearing loss or surgeons, otolaryngologists, for example. We had this dream. Let's just do a podcast. You jumped on board and you were so great at doing that.

Sofia Olaizola: I thought that it was a really good idea, because I personally listen to a lot of podcasts on my way to work or my way home from work, or when i'm doing house chores, and I can't like dedicate my visual and audio attention. It's a really great way to get your message across, because people don't really have the time to go and look through research and see what's new in the research. Having these discussions with other researchers across the world, and talking about their experiences and some of the things they're working on. Their lab is a really great way to get people involved in the hearing world, and to understand what that even entails like, what kind of solutions to problems we're looking for, because they may not even know there are any problems in the first place

Maria Khan: I've done video editing. So I came in here. I'm like oh, it's it's It's the audio version of it. Podcasts are like a great way to help disseminate information and knowledge, unless you're at the university, higher academia research is not something that's on your mind all the time, I think it makes it really accessible to people who may be interested, but they just don't know where to go like to learn more about research.

Karen Gordon: We done a lot of work trying to put these also into transcript forms for people to read because we we can't give those captioning like you talked about when you're watching TV. So this was the best way we thought to give people access. Are you happy with the result from the first season?

Sofia Olaizola: The first season turned out really great. It was our first try, so it took a little longer. But I think that now that we kind of got like a system going, we’ve got the hang of things. I thought that all the episodes were really good to listen to. Because I listened to it a thousand times, before there was even any music or anything, and I was like, Wow! I think that this is actually a really really interesting podcast. I think a lot of people will like it. I also thought it was cool, because I'm hearing from researchers I've never even heard of before. And even though I'm so interested in auditory research, I didn't even know who these people were. And now I do, and it's like I know what kind of research they're doing. And so in the future, if I want to look for research, I can look up their names and find out what they're doing. And so I think it's very useful, especially for students in university who are planning to go into speech pathology or audiology fields. I think it's a really good way for them to get exposed to like what they would be looking at if they pursued a masters in audiology or speech, language, technology.

Karen Gordon: That's such a good point. What about you, Maria, what do you think? Are you happy with all the work you did?

Maria Khan: Oh yeah. Everything I learned was very new. I had a general understand what audiology research entailed and what CI research entailed but that like broadened my horizon by like ten-fold, because you're learning about topics that you haven't even thought about before. I think Ruth was talking about bilateral hearing you like, How is the impact of CIs? You're like, I like not as a non-CI user, I'm like, oh, hey, just put two and two together You're like, okay, that makes sense like why they would want to research it. You and you also think it's really cool that we learned of the motivations of the researchers, and why they want to get involved, I think, for Renee, she did because her grandfather had hearing loss, so that's like encouraged her to go into audiology. So you're learning more about the researcher of themselves, like who they are as a person what they are like, I think like the podcasts talks about mentorship, working as a team. How to be like a great clinician and researchers combined. It's a great way to like have all this information like at your fingertips.

Karen Gordon: You guys have been an incredible team. It has been such a pleasure to do this all together, and we really put a lot of time, heart, soul, effort, cognition, hearing into it. I'm really glad to give you guys a space to come out from behind the sounds and the transcripts, and into the direct auditory part of the podcast. I have literally watched you guys grow up, and that is such an honor for me. I can't tell you. Well, I have told you before that I am just so happy to work with you but I’m also so proud of you and everything that you do. So thank you for being involved and being part of the team, and I hope this is an episode that many, many people listen to.

Sofia Olaizola: Thank you for having us.

Maria Khan: Thank you. Honestly, it was a great time I had fun.

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Karen Gordon: You can catch other episodes of the Hear Here podcast. There's a link on our website, search Archie's Cochlear Implant SickKids Research Institute or wherever you get your podcasts. The Hear Here podcast is put together by me, Dr. Karen Gordon, with my colleagues at the hospital for Sick Children in Toronto, Canada, Drs Blake Papsin and Sharon Cushing with a tremendous production and advisory team, Sofia Olaizola, Rachel Bedder, and Maria Khan. Our wonderful Hear Here podcast music was composed and performed by Dr. Blake Papsin.

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