

## #11 Hearing Wellness Journey Podcast

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- [Narrator] Welcome to the "Hearing Wellness Journey Podcast", an exploration of determination, hope, self-discovery, and triumph. We'll share the personal experiences of those that are living with hearing loss and provide a Haven for their stories, to show others that they are not alone in this journey. Please welcome your hosts, Dr. Dawn Heiman and Lindsey Doherty.

- Welcome everyone to today's episode. We have an audiologist, again, of course, and her name is Karen. And she is a special person, because she and I were talking about it before, I had no idea that she had a hearing loss. I just knew that she helped kids and adults with rehab and all of that. And then it just came up one day where I just, I had no idea because we don't live in the same town, we've never met face to face. I just knew that she was a special audiologist doing special things. And she happened to mention about a struggle that she was having. And I said, you know, I think if you tell your story, you could help more people. So welcome Karen, thank you so much for being here.

- Thank you so much for inviting me, Dawn, it's an absolute pleasure to be here with you. I have so much love and respect for you and your work. I'm ready to go.

- So where did you grow up? Where are you from? What was your childhood like? Like take us back way when, to your family and where did this all begin?

- I am from Toronto, Canada, and that's where I live right now. And I'm gonna have to go right back to the beginning so that you can get some information about the etiology or that kind of stuff. My mother was pregnant with me, I have two older brothers, and she had toxemia while she was pregnant with me. And then when she was giving birth, we had complete placenta previa. And so by the time they got ahold of me, I was very sick, I wasn't breathing was just full of fluid 'cause I had aspirated everything. And so I was giving some antibiotics, which I did not respond very well to, impressed with the oxygen loss, there were a lot of things that would be responsible, I think, for the hearing loss that I have. Now, the only thing the doctors told my mother to look out for was her eyes, and she might have some cognitive delays or deficit, nothing about hearing loss. And this is back in the 70s, I'm not ashamed to say that I'm a 1971 baby. So that means I just turned 50. So, Thank you. So, everything, I met all my milestones, but I was a very quiet baby. My mother didn't really think too much about it, except she noticed when I was 18 months, that I was not responding to the upper end of the piano. And she's a musician, she's a piano teacher, she plays the piano all the time. And she noticed that I was not responding at all to the upper end of the keys. So she took me to the doctors that I am concerned about her hearing loss. He would clap his hand, I turned my head and no, there's nothing wrong. And she kept going back and back and back and back and back. And this guy said, leave me alone. And finally, when I was three years and 10 months of age, that's a long time, my mother, I wasn't even talking, I looked like I was trying to understand what people

wanted of me, but I wasn't able to follow through with directions or really show understanding. So my mother was like, she has got to have something wrong with her hearing. And so at three years and 10 months of age, she took me to the doctor and she said, "I am not leaving here, I'm not leaving here until you get me an appointment for a hearing test with an ENT." So he's like, "Fine, I will send you to the hospital for sick children in Toronto, just to get you off my back." So she managed to get an appointment for me that afternoon. And the audiologist diagnosed a mild to profound hearing loss. So we're talking about 125 Hertz, a mild hearing loss, for those of you who don't understand audiogram numbers. And at 500 Hertz, it was a moderate hearing loss, 750, it was severe, and at 1000 Hertz, it was profound, and it rose up a bit at 4,000 Hertz. So in other words, I could hear men's voices. I could hear voices, but it just all sounded like mumble and jumble for me. And I could hear my mother playing the piano, but I could only enjoy it if it a low frequency loaded song, like "Moonlight Sonata" by Beethoven. So I used to sit there for hours underneath the piano, right up against the board of the piano and watch my mother push the pedals while she's playing the song. And whenever it would go to that high, the high keys, I would bang my mother's legs, because I would think the song is done. You know, I want more. And anyway, my mother was... and they tested me twice, they couldn't believe it. And so at that point, the ENT said to my mother, there's really nothing we can do for your daughter. And the audiologist was standing in the room and he was very quiet, and his name is Hank Victor. And he was there, he had just graduated from Kent University in the United States, moved up to Toronto, thank God, and he was standing there, and listening to the ENT tell my mother all of this stuff, like, she's not gonna benefit from hearing aids, she's not going to learn how to talk. It's too late, you got to send her away to a school for the deaf so that she can learn sign language, if she can learn it. And maybe, maybe, she will be able to learn to read and write, maybe, but that's only at a grade three level. Such low expectations, even to make a recommendation for someone to go to an ASL school, which is a great recommendation, nothing wrong with that. But to say that, if I go to a residential school for the deaf where they're learning sign language, the best that they can achieve is grade three. What kind of like, that's just, I don't know. So that's just wrong. So my mother said to him, if you want my mother to do something, just tell her she can't do it. Just, yeah, and so he says, "Well, she's not gonna learn to talk." And my mother says, "Well, she will learn to talk, if you know, she will learn to talk if it's the last thing I do." So I think a parent's instinct is really powerful. If they wanna do something, they will find a way to do it. And so you just have to sit down, listen to the parents, and ask them, "What are your desired outcomes for your child?" My mother identified what her desired outcomes were for me and shared them with the ENT. Luckily, Hank was there listening. So once the ENT left the room, Hank came up to her and said, "Did you know that BTEs have just come out on the market? My mother is like, "What's BTEs?" He said, "Behind the ear hearing aids. And they are so powerful, would you mind trying them?" And my mother's like, "Are you kidding me? Of course, I'm gonna try them." So we ordered the hearing aids, and Hank was the angel that really gave me... he believed in the opportunity, he gave me that opportunity to join the hearing world. And that's what audiologists do. And I... anyway, I cannot go on and off about Hank, but anyway, I'll continue talking about him. One week later, we managed to get an appointment. Now, before I talk about this appointment, I wanna tell you that I was a little kid and 50 million extra curricular activities. ballet, baton, figure skating, I mean, come on, it's up in Canada, we got to do anything with ice, right? She thought, mother's instinct, if she's around other children, she's going to learn

to talk or she's gonna want to talk. She had no idea. Well, she did have an inkling of a suspicion of the hearing loss, but she just wanted to give me every opportunity. So I was in ballet and we were in the rehearsal time, you know how spring happens, and that's rehearsal time for ballet and all that fun stuff. And there's a picture of me, can I share this picture with you? Do you see it? Now, look at me. Now, for those of you who cannot see this picture, there is a three year old, almost four year-old girl in his beautiful baton costume. And her leg is kind of twisted and her arm is above her head holding this baton in a half-life manner, if you will. Like I don't look like I'm excited to be there, right? You see, and the most significant part of this picture is I look miserable. And I remember that day like it was yesterday because the photographer was telling me what he wanted me to do, what kind of pose to do. And do you think I could understand what he wanted me to do? No. But from his perspective, he's thinking here is a child who is not following directions because she just wants to be noncompliant. And so he was getting angrier and angrier. And so he came, he asked me to pull my hand up with the baton, and I didn't. And so he came over, pulled up my hand and yanked it, like really roughly, 'cause he had had enough of what I was doing, what I wasn't doing. And it hurt me. And I was so eager to please this man, but he was angry and I felt sad because I disappointed him.

- I'm so sorry.

- Yeah, so there's that disconnect there. And you can see that I'm not with the world, okay. So this was one week before I... come on, this is three and a half, for a couple of months later I was diagnosed with this hearing loss. And so then I got the hearing aids, and I remember that on the same day, I had the baton performance, the actual performance, of the the UN event. And so that morning I went to Hank to get the hearing aids. And he put the ear molds in my ear. And I remember it being very sticky. You know how it is when new kids get it, it had hurt a little bit. He's pushing it in, and I'm like, "Hey, I don't want to wear it." And he turned it on and the room started to glow this golden yellow. And I'm not kidding, before, my life seemed like a black and white motion picture, like a Charlie Chaplin picture. You know those, and people would come up to me from here and there and I wouldn't, like, it always scared me because just life seemed to be going so fast in front of me and I couldn't keep up. But the room started to glow this golden yellow, and then I started making some vocalizations. And that was the first time I heard my voice. And my mother said that I was like, "Ooh." And then I would start to laugh. And so then we went home and it was raining that day, and we had that plastic clear head rain cap that the ladies used to wear. And my mother was petrified of getting my hearing aids wet, and I could hear the crinkling. And I was just like, we will running across the street trying to catch the subway, and I could hear the splish-splash and the crinkling. And I was like a little bit alarmed by it, but curious. And so the world started turning blue and teal. And then we got onto the subway. I do not remember that, but my mother did. She says, "You screamed . And she's like, and then halfway through the screaming, she realized, oh my gosh, she's never heard this sound before. And she's still scared, and then by the time I get into the car, the world became... The longer I wore the hearing aids, the more colorful the world became.

- Wow.

- And that night we were in our baton rehearsal and we were all supposed to be doing our thing. And the song started, and the song was called "Raindrops Falling On My Head". And that was the song we had to perform to, and it was the first time I heard a man sing. ♪ Rain drops falling on my head, poo poo poo poo ♪ And when I heard that song, everybody else was starting to dance, but I just stood there, I was frozen. And I was just like... like, wow. And then I just started laughing and smiling and just listening. And I was wandering all over the stage in amazement while all the other kids are dancing. And the mothers were pouring their eyes out in the audience. My mother was bawling because it was the first time they saw me become really connected with something that was happening around me, which is the music, of course. So I'm gonna show you what a difference it makes when you can hear like I could. Now do you see it? No, you don't.

- Yes, oh, it was there, let's go back.

- Okay, do you see it?

- Yes.

- I don't think I see it.

- I see it, you look so happy.

- Exactly.

- You're adorable, yes.

- You see the change in the pasture.

- Yes.

- The light in my eyes, that connection, I'm with you, I'm smiling, I'm doing exactly what I'm supposed to do. So I love to show this to audiologists because I teach every once in a while the oral rehab class that audiologists and speech language pathologist have to take together at the University of Western Ontario. And I tell them, you cannot imagine the impact being able to hear has on the child's body and the child's emotions, their feelings, their mental wellness, it just affects everything in their life. And that is what Hank did, and that is what audiologists do. And I, from a very young age, I decided actually, I'm going to be an audiologist so that other kids can get what I got, you know? So that's my early life, and yeah. And then I wanna talk about another period in my life, that is very difficult, that will be difficult for some parents to hear. Because it is a reality for some children, some children with hearing loss, not all children, but it's really, really important for parents to know that their child hearing loss is not the parent's fault, it's not, okay. The children do not blame their parents for their hearing loss. Yes. Okay. Maybe they'll get older and know that, I wish, but that doesn't mean that they are blaming the parents. And thirdly, the kids will love their parents, and more importantly, kids will see their value reflected in their

parents' eyes. So the child will think of himself or herself or themselves in the way that their parents view their child. So if the parent feels guilty and they're upset and they're depressed and they feel like they have to, oh, you know, maybe I shouldn't discipline the child because, well, you know, but he didn't understand, maybe he didn't understand, then they're going to know, they're going to think that way themselves. Does that make sense?

- Absolutely, and also the siblings might feel a certain way if the parents treat the child with hearing loss in one way, but treat the others in a different way. It's so complicated, it's hard to be a parent to begin with.

- Exactly, and you know, I just am begging families, every family that I work with, you know, please just, if you want to do something that the best for your child and you want them to learn to listening and talking, you want them to be successful, and don't think you are not doing enough because the biggest thing you can do is love and enjoy them and have fun with them. The more fun you're having with your kids, the better they're going to be able to learn, and the better they're going to feel about the world and the better the outcomes will be. And so many parents, I think, puts so much pressure on themselves and I really want to let them know, please don't, it's okay, it's gonna be okay and we love you. We need you and we need our grandparents, we need our siblings. Our siblings need to tell us things like, my brother once told me I was so upset because I didn't have a boyfriend. You know, every teenager wants to have a boyfriend, and I couldn't find a boyfriend, 'cause none of the boys asked me out or anything. And my brother said, "You know what?" He says, "You are so, so lucky, because your hearing aids are actually just screeners. You know, if they can't look past the hearing aid, then they're not worth being with, period."

- What a great piece of advice or a perspective, I like your brother.

- I do too, he's been a great guy. But going back to the hard stuff, because we wanna talk about the hard stuff. And so kids that is being bullied in school because they have a hearing loss. Now I was one of the very few kids who were lucky to be able to go into a experimental study, designed by the Toronto District School Board and Phonic Ear, do you remember Phonic Ear?

- I do, I remember those little antenna things, even more into the 90s, but yes, Phonic Ear had FM systems, the plugin, you name it, you tell me, I'm sure you know, you lived it more than I did, yes. It was a hearing aid manufacturer for kids hearing aids and for schools.

- Yeah. Yeah. So if you wanna know what the Phonic Ear looked like, just get the book called "Ei Deafo". I cannot remember who wrote the book, but you can look it up, I'm sure Sean, Don will.

- I'll put it in the resources. I don't have a copy with me, but yes, it's blue, yes.

- Great book, it's very cute, very funny and very accurate. Now there's a little box sitting on the chest, about this big and it had wires, and it connects to an ear mode inside your ear. And it's basically a radio device that communicate with the microphone or the transmitter that the

teacher wears that was long and slim. And it looked like that, and she wore it around her neck. And so it didn't matter where I was in the school or even in the class... No, it didn't matter where I was in the classroom or even in the school, I could always hear the teacher's voice if she had the microphone and the transmitter on. And I loved that thing. It was great because it got rid of the background noise and I could focus on the teacher voice and really pay attention to what you wanted to teach me. I never went a day without it, and was very proud of it. Now, when I got to grade six, I started getting notes in my desk, excuse me. I started getting notes in my desk, like, "Beg your face, Karen," "Deaf and dumb." Wires, you know, pictures of me with like, I had the Farrah Fawcett hair style back then, which we looked awesome. And hair like this.

- I believe it was beautiful, they were jealous of you, let's be honest.

- Probably, maybe, maybe. That's an interesting, I never thought of that.

- Please always make fun of those that they're jealous of, because they wish they had what... usually there's something internal they're going through and they want to put you down, so you don't feel good about yourself.

- That's exactly it. And you know what, Dawn, that is exactly what my father told me. You know, my mother did all the therapy, she did all the work, the fun stuff with me. But my father was the one that told me things that you just said so beautifully and so eloquently. And he said, "Karen, they're just trying to draw the attention away from themselves, and to pick on someone who has something visible, which you do." And he says, "Now what you need to do, is you need to teach them, you need to show them that something like that does not bother you. Because if you show them that it doesn't bother you, then they're not gonna do it anymore." And I said, "Well, how do I do that?" And he says, "Well," he said, "Do you have those notes?" And I said, "Yeah." So he says, "Let's make a poster." So we put all the notes, we glued them on a poster, and he actually framed it, like, who would do that? But, I mean, I can't imagine how hard it must've been for a parent to do that with their child, but he did it. And he was just like, "Oh, look at this picture, This person, . Look at the way they do this, oh this is classic. Oh, did you see her printing is not very good, did you notice that?" Like, really using a sense of humor. That's what you gotta do. You gotta model how you should look at the world. And that's what my parents did. That's what my dad was so good at doing. And so he says, "Now I want you to take that frame and take it to school and use it for show in town." You'll figure it out. I was like, "Okay." So we used to have to eat our lunches in our classrooms with the poor teacher, she never got a break. So during lunch, I stood up on my chair, I got this poster, stood up on my chair, and turned it around, showed it to everybody in the class, disrupt them eating their lunch. And the teacher was very interested. She's like, "What'd you got Karen?" And I said, "Well," I said, "This is a picture. Inside this frame contains all of these notes, beautiful notes of love and encouragement, and really nice pictures of me too. And all of these things that I've found in my desk every single day that I've started school here. And I loved them so much that I decided to make a frame out of it. And I'll put it on my bedroom wall so that every morning when I wake up, the first thing I see is this frame, and I will be reminded how much everybody in my past loves and adores me. The teacher was like, "That is so nice, Karen." And you could see, can you imagine the rest of the class?

- Wow.

- So the teacher, she's like, "Let me see, let me see." And so she looked at every single picture, and she took her time and she just looked up at me. And when she was finished, she said, "Karen," she said, "I want you to take this to the principal, and show him how beautiful this piece of artwork is. And I want you to tell him that Mrs. Peckham sent you." Okay, and she says, "And you tell him what you told the class. I think he would be so thrilled to hear it." I thought oh, oh. So I took the picture and you what I heard what she said to the class, because guess what? She was wearing the transmitter.

- Nice, so you walked down the hall and you could hear, she thought she was privately talking to them. Okay, what did she say?

- She said, "I have looked at every single note, every single picture, and you know it's so unfortunate that I know the writing styles and the drawing styles, and I know exactly who wrote these notes and drew these pictures. And I am so disappointed and I am angry, and you will be sent down to the principal's office to be dealt with. And if I ever, ever see you or hear from Karen that you had made any more notes or have said cruel things to her, I will make sure that you never ever do it again or something like that. Like she was so, oh, like, she really gave it to them. And I thought, oh, oh, so I guess that's what, my dad meant. And I never got another note now or a picture. And what turned from bullying, it turned from bullying to just silence and just stay away from her. Though hurtful, but I did have that one friend or two or three that had something else different about them. And do you know what was great about that? I got to learn about diversity and to celebrate them, which, you know what? I would not change a thing in my past. You just have to look at things that have happened in your life, that you might think of negative or very difficult to deal with, and you've got to see or find the positivity, the positive in it, and you can.

- Yes, you can. It's not easy sometimes, or sometimes you don't know why, whatever it is is happening to you, but they say what doesn't kill us makes us stronger. So going through a mortifying situation, hitting your head, your dad was fantastic with laughing at every single one of those notes, or maybe the misspellings, the poor handwriting, the bad drawings, and allowed you to say, "You know what? I can laugh at them and make fun of them right back." But you didn't do it in a cruel way. You didn't complain and you didn't tattle, he helped you to deal with this in a positive manner and show what they've done. But sometimes yeah, when someone is being cruel, best thing you can do just internally is pity them. Like, I feel really bad for them that they feel the need to do XYZ, must be miserable to be in their head.

- Yeah. Yeah. And I guess, you know, best thing that can do is just sit down with their kids, talk to them about that, and kind of teach them some really great comebacks.

- Absolutely, and teach everyone. Try to talk about diversity, empathy. What if this happened to you? You know, it's not just you, but your siblings too. It'd be like, "You would never do this to

another child, would you?" This teaching point, if you see someone being bullied or someone being isolated and not being brought in, it's your job to pull them in, it's your job to stand up to that bully.

- Yeah. Yeah, yeah.

- It's hard.

- It is. It is. And you know, at the time I was devastated, but, you know, I'm so lucky to have had that experience with my family supporting me. And this is what parents and audiologists too can do because Hank was there as well, and he was my audiologist. From the time I went to university, I was allowed to volunteer. And this is another thing, this is why I love what you're doing, because I had always wanted to be a doctor. And I thought, nope, I can't be a doctor because I can't hear the stethoscope, hear on the stethoscope. But I thought that door was closed, but I really wanted to be an audiologist. And the reason why, was because I loved hearing so much, and for me, every single time the hearing aid broke down, was on a weekend, was on the holiday, was on vacation.

- Of course.

- Just silly things like the tubing cracking. You know, and you wouldn't have a tube, and I'm like, you know what? I decided I am going to be an audiologist so that I could look after my, I can fix my own technology whenever I want. I can make sure I'm getting the best hearing aids and do all the cool things that Hank does, you know?

- Yeah. And I thought, but I don't know, I know you have to listen to hearing aids and I don't know how I'm gonna do this. Hank was like, oh, you can do it, Mark Ross." And I'm like, "Who's Mark Ross?" And he's, "Oh, he's the coolest guy. He's got a hearing loss too, and don't let anybody tell you that you can't be an audiologist because there is someone out there doing exactly what you wanna do." So I learned everything about Mark Ross. I had to talk to him, I had to get to know him, and you know, I've never met him, but I would love to meet him just so I can say to him, thank you for giving me that inspiration to say, well, if he can do it, then I can do it too. And this is what I love so much about this podcast, is because you're bringing on people from so many different walks of life, and that's what kids need, that's what parents need. They need to see their dreams for their kids coming back to life, you know, because they die for a little bit when you find out like the diagnosis, but we don't have to, we can resurrect those dreams saying no problem. So, yeah, and this is why I think it's so important to have a community of people who are just like you so that you can learn from each other, getting coached from another, and so that way I love you, Dawn.

- Oh, I love you too. And I love that you said, you know what? I wanna do this, and then your audiologist said, well, you know what? You can, and your journey takes you on a different road. And when you listen to hearing aids, you know, it's funny, we're all learning now, we shouldn't just be listening to hearing aids. We always should be putting them into the test box. We should



be doing things differently visually and not base it on what we hear. So the work arounds are definitely there. Where there's a will, there's definitely a way.

- That's right. Same thing with that speech discrimination testing, I thought, oh gosh, how am I gonna do this? And my audiologist that Dr. Brandy, he wrote a chapter on speech perception, testing and Jack Katz, the Bible of audiology. He said, well, first of all, he said, don't worry about the speech, 'cause I was still worried about my speech because I came from an undergraduate program in the states. I was born in Canada, but I went to the states to get all the good stuff, all the good education in audiology. They had an undergraduate in place for communication disorders. And the professors would be trained Pathologist, they didn't really know a lot about audiology. And they were mostly concerned about my speech and how I'm going to do speech perception testing with this. "Don't worry about that," he says, "You gotta use recorded material."

- Right.

- And we all know that. He said, "Secondly," he says, 'About the responses." She says, "You can get them to write it out." And I'm like, "Really?" And he says, "Yeah," he says, "Just get them to write down the word." He says, "Get them to say it out." He says, "I bet you, I bet you," he says, "I will make mistakes too." So he set up a contact, if you will. He says, "You get your clients to write down what they heard and will write down what they said, and we'll see how close everything matches." And he actually made some mistakes too, not a lot, but he was like, "This is the way to do it, Karen." Then I learned to do it this way with parents, where I would have, you know, if the children came and needed a hearing test, I would ask for both parents to come, why? Because halfway through the list of 50 words that were recorded, I would have one parent sit in the booth and write down what they heard their child say, and what they heard themselves. And then the parents sitting outside the booth had to write down the responses of the child. And it was there to help me secretly, but you know what? It helped the parents because halfway through the test, they were like, "Oh my gosh, like I had no idea that my child was hearing this word in a different way." And that helped them understand, right even before I got to the audio gram and the hearing test. They sit down, this is what your child is understanding, you know, and they got it. Like they got it and they loved it. And so, you know, sometimes the creative solutions that we rehab to use to help us do the job in an effective way, actually turns out to be a great counseling tool for parents and individuals as well.

- Absolutely it's hard to know where the breakdown is, and it's always helpful for the professional to be able to show you or give an example that makes sense, so that when they go home, they understand what just happened, or where are we going from here or the wow effect of, "Oh my gosh, I had no idea, thank you for showing me and involving me." So yeah, that's, I need to start doing that.

- Just an idea. And so when I went to the University of Akron, which is where Carol Flexer was, and that's where Hank wanted me to go. He wanted me to go to Kent, but he said, "By now," he says, "You know what?" He says, "The University of Akron, is a better choice," at the time, at the time, just at the time. And he says, "You are going to love Carol Flexer. And I did, and I was one

of the first, I was the first person with hearing loss to go through the audiology program. And then after me, so many people came after, like Carrie Spangler, I don't know if you know her? Stacy Lamb, and a lot of really, really great people who are in the field today. So I'm very proud of that. How did I get onto the topic? I can't remember.

- That's okay, we can go back. So can we talk about, was there ever a struggle during, let's say the bullying or grade school or high school or college where you said, "You know what, I'm done, I don't wanna wear hearing aids." Did you have a rebellious time in your life ever?

- No, I know a lot of people have, I've never had that.

- It's okay, and that's just you, I was just curious.

- That's just, yeah, yeah.

- Can we fast forward through time or can we go to graduate school, when you started to learn about the technology. And when you're in graduate school, sometimes you get access to new stuff or you get to be like the hearing aid rep skinny pig. Was there any wow moment when you were in graduate school where they said, you know what? I know you're wearing this, but can we try something on you?

- Not so much in grad school, and it was nice to be in grad school, it was nice to go to AAA or the big, big conventions where you got to talk to all the manufacturers, because I loved being on top of the hearing technology. And when I was in graduate school, that's when the, DigiFocus came out for the first time? That was the first digital. But back then, it wasn't powerful enough for me to benefit from a hearing aid like that. So I will tell you that about, I did have a moment as an audiologist, and by then I was working at an oral rehabilitation, that's what I really love to do. You have a certificate behind you called Disney University, I wanted to be in Disney every day with the kids. I just love playing with them, I love working with parents, teaching them strategies that facilitate the development of listening, talking, and thinking and making sure they get the best audiologic management they possibly can. And one of the... I shared a lot of kids on my caseload with the University of Western Ontario, Marlene Bagatto, Susan Scollie, Richard Seewald, the big guns in audiology. And they knew that I had a lot of kids for sloping losses. They knew that I had a sloping loss, and the challenge was always getting hearing aids that could give me audibility for S, and F, and TH, which is very difficult to do with my degree and configuration of hearing loss. And so this was before, about three years before frequency compression hearing aids came out on the market. They had prototype models from Phonak, and Susan and all her students and her colleagues who were working on, how well does frequency compression work, and how far can we push it? And so when she fitted the frequency compression hearing aid on me, we pushed to hard and I could actually hear an S. I never, I mean, I'm an audiologist, I know how hard it is to get it. I could hear it with the Phonic Ear, but it was extremely difficult to hear it with the hearing aid. And I just never dreamed that it would ever be possible. And I remember sitting there and we tried on those frequency, you know, the sound recover function on those Phonak hearing aids, and I started to cry, and then Susan started to

cry. Then Marlene started to cry, you know. It was such an incredible moment. And I can't describe how delicious, how delightful it is to look at it. It was just miracle, really?

- What year is this, like 2005?

- Younger than that, yeah.

- They were doing research, it's before they brought it to market, obviously, and they were testing this.

- Very, very early, this is back in 1999, 2000, 2001.

- Wow.

- I shouldn't even be telling you this.

- No that's good. I didn't realize that's how long they worked on that. That's brilliant.

- They worked so hard on it, and we were testing the hearing aids out. They would spend... it wasn't uncommon for me to go down there and spend six hours there in the lab, trying out the aid. And there would be distortion, which ended up being the feedback manager, being pushed to its limits because the ear molds were not fitting tightly enough, but we couldn't figure out where that distortion was coming from. And I was just so inspired and so amazed and so touched by the whole team's dedication, their passion, their commitment, their persistence in trying to help me, to help me get the benefit of that particular technology that was so hot off the press, kind of behind the scenes. And it was really incredible. And that was at a time that I was trying those investigating whether a cochlear implant would be for me. And to have that as in that one year was just like, oh, awesome, so yeah.

- Wow, so when did you decide to get a cochlear implant?

- That's a good question. And when I was in university, this was back and 1994 and in 1997, in grad school. When working with Carol Flexer there is an auditory mobile therapy program, and the approach works with all children, with all degrees of hearing loss, even profound, severely profound, and Carol while the one audiologist to other kids who were newly diagnosed with severe to profound hearing loss, you wanted to go to Carol. And so I was her student and I would watch her work with the families and she would test her hearing and she's brilliant, pediatric audiologist, just brilliant. And she would counter these families and they would ask her, "What hearing technology can I use? Which one will be the best for my child?" And she would say, "Well, you know, there are hearing aids and they can do this and they can do that, but have you ever thought about a cochlear implant? And the parents would be like, "No, no." And I could never understand that as a graduate student, I'd be like, you know, like, "How could you not give your kids, like, how could you be so resistant to a technology that can open up the world?" And I used to be like, so, mm, mm, mm, about it. And then I got a job in Toronto and I'm working in at

the Learning to Listen Foundation, which is one of the largest clinics for auditory verbal therapy for kids. And we had kids that would come in, they would do therapy. They wouldn't be able to hear, and so we would recommend, maybe you should reach out to the cochlear implant program to have them assess you for your candidacy. And the parents would be upset. And I just couldn't understand it. And then I went to the hospital for sick children for another patient, and we had a break. And the audiologist said to me, "Karen, have you ever thought about getting an implant?" And I remember, okay, I'm so ashamed, but I'm gonna be honest. I remember calling my chair back and saying, "No, why would you wanna put an implant on me? I'm doing great with my hearing aids, thank you very much." Not in that way, not in those words, but that was how I felt on the inside. And then I thought, oh, wow, I had a lot of nerves.

- Perspective is everything, right?

- I know.

- As an outside, it seems so easy, when it's you, you're like, "Wait, what?"

- No, no. And I thought, you know, like, ah. And the audiologist kind of smiled, and she says, "Well, what's that all about?" You kind of bounced back about a couple of feet there. And you're, like, and I said, "Well, do you think I need an implant?" And she's like, "Well, I think you can benefit from it, it would be really helpful for you." And I'm like, "Why? What's wrong with the way I hear? What's wrong with all of the years of effort that my mother put into me to get this, this, this, and now I have to say goodbye to it, because it's not good enough." And she said, No, no, no, no, no, no. It's not that it's not good enough, but we have something that will give you even better access to the world." She says, "Just change, something to think about." And she didn't push me. I learned, I learned so much from that, Dawn, because I learned that you cannot push someone to make a decision, however good you think it might be. But parents have so many different emotions and you don't know what they're thinking, unless you ask them and unless they tell you. And many time, you know... So I'm ashamed to say, well, I did go for an investigation in 1999. I was declined candidacy, which surprised me, but they said I do too well with my hearing aids. And without my hearing aids, they said, you surpass the 30%, like you get 40% speech discrimination without your hearing aids. Why would we put, and that's our criteria for hearing aids? Why would we put an implant on you? So remember I was telling you that, you know, if you want my mother to do something, just tell her what she can't do.

- Right.

- Yeah, if you want me to get upset and more laid down, like I wasn't all that thrown about an implant, but the surgeon did me a favor. He said, well, you know, sometimes he says, you know, you can't have an implant. And I'm like, well fine, I'm going to show you and I'm gonna get it. And he was talking about all the information, like he was trying to get me out of the clinic, right. By giving me a little bit of like comments, like, you know, well, you've never heard an S, so if you've never heard an S, then you're not going to be able to hear an S with an implant. And then I'm like, well, "Okay, With all due respect, I work with babies, they get implants, They've

never heard an S. All I need is for them to have auditory access to the S. And it's my job and the parents to teach them what that S is all about. Good point, well taken, you're not getting it. I'm like, mm, I'm gonna get it.

- So what did you do? So what did you do?

- I went to the states,

- , Like, I'll get an implant. He told me, no, oh no, you don't tell me no.

- That's right, and you know, he's like, "Unless your hearing changes," he says, "You can't come back for another assessment and totally you're after." And I understand, you know, with the system, the way it works up here in Canada with social medicine and everything. But I'm very pushy when it comes to myself, I want to have the option, whether I want it or not, the option has to be there for me. So I went to New York, went to beautiful, I'm gonna be very careful with my names now, a beautiful cochlear implant center in New York. And they declined me the first time, then I found some holes and made my audiologist argument. And then they said, "Okay, Karen, you've got one ear that's approved. You made your point in your case and you're absolutely right. We will approve one ear, but we want you to think about it for three months and then we will do it. And I was all gung ho about it and then I got pregnant. So then I had my beautiful baby, and then she was struggling with language, in spoken language development. I thought she had ANSD, I was testing her up the wazoo, and you know, but she had challenges. So I decided, you know what? This is my time to be a mother and to look after my daughter. So that took five years. And then after that, as I was working, I saw a patient who had exactly the same hearing loss I did, same hearing technology was doing just as well as me. He got an implant and his body rejected it. And he did so well with it initially, but then the body started over time, within six to eight months, his body started rejecting it and quite bad. And it's so, so rare. Like I've never seen a case like it ever.

- I've never heard of a case like that, that's terrible.

- Yeah, and I've never seen it in all my years up to date, it's just only him and he lost an ear. And that shook me to the core. And I thought I have to be prepared to lose my residual hearing, number one, I have to be prepared to accept a cochlear implant failure if it happens, very rare, but I have to be prepared for that. I have to be prepared for every adverse reaction. And to know that I knew about it and, oh, well it happened, but I have to accept it, you know what I mean? Took me such a long time. And so in 2009, I found a surgeon again, still in Canada. You do too well for an implant. And so I thought, okay, that's fine, I'm gonna find the surgeon I like. and I found a surgeon I absolutely adore in Germany, One of the best surgeons in the world. And why did I choose her? And so maybe this is something that would be helpful for professionals and parents. I asked her one question, and that was, I said to her, "I know you are one of the best surgeons in the world. I know you have a beautiful hospital. I know I have great anatomy. But you are only human, humans can make mistakes, and I'm okay with that. I know devices can be lemons or they can work really well." And I said, "I need to know what you will do if I have a

problem with the implant, what will you do?" I said, "Will you have..." And she said, "You know what?" She says, "I'm there for you because the minute I put an implant, I open your skin," she says, "I am responsible for you for the rest of my life."

- Wow.

- And I said, "Okay, I'll put my head on a pillow for you." Now, interestingly, in 2009, in November, 2009, I got the implant, it was activated in December 14th. Not only did I have a great surgeon, I had great, they call them engineers in Germany, cochlear implant engineers, or audiologists for all intention purposes. And I had my oral rehab therapist from when I was a little girl.

- Wow.

- He was my boss, too, as we worked at the Learning to Listen Foundation, but I had him with me, because to me, you can put any device on your head, but we're actually hearing with the brain. And when the brain is receiving new auditory input, that is very different, it's going to have some time, it's going to take some time to adjust to it. It's gonna sound very different from what you've heard. Now, I knew this as a professional, but it was almost like when I went there for my day of activation, the professional, my body's split into two. There's the personal Karen, who just wants to hear well, who knows nothing, and the audiologist Karen, who knows a lot about rehab and audiology. The professional Karen, she went on vacation to Bora Bora. She was not coming back, and I felt helpless. Do you know what I mean? And I thought, oh my gosh, this is how it feels. And I was crying, I hated the sound of it, it sounded very quiet. Some things were really loud and other things I could barely hear. And I thought to myself, okay, Karen, when you get back to the hotel, you can take the implant off. And I actually had phenomenal residual hearing from the surgery. Usually when you have surgery, you have to expect to lose all of it or much of it, this surgeon was able to prevent... She was able to preserve 100%. The audiogram was exactly the same, I couldn't believe it.

- That's cool.

- Yeah. And so I could wear the hearing aid, and I'm like, I'm not gonna wear that implant. I'm just gonna take it home or take it back. And like, this is me, okay, I'm a professional, like I should know about this, but I was, "Nope, I'm gonna take it off."

- So can I ask a question? So did you move to Germany for a couple months?

- I, well, that's a great question, my husband's German. And his family is in Germany, they lived in Berlin, and I had the surgery done in Freiburg. And so, yes, we only had to stay in Freiburg for a week. In Germany, in Freiburg, they make you stay in the hospital for a week, which was phenomenal because I had care every single day. Any questions or any recovery freak out that I had, were completely solved by the ENT on staff, it was great. But I was just in Freiburg for a week and then went back to Berlin and I recovered. And I loved it because in Canada, there's

my family, not only my family, but all the families on my caseload that I worked with, who were so, "Karen, Karen, how does it sound, how does it sound?" And I just needed to be away from that, 'cause I didn't want the pressure in my family in Germany. They didn't know what to expect. They were just like, "Okay, whatever, whatever, you just tell us what we need to do and we'll do it." But that week that I was in Freiburg for the activation, I was there for a week and I had my oral rehab therapist there, Warren Estabrooks. And yeah, I had to put them up in a nice hotel. And he was worth every penny, because in that session, he was there with me and he said, "Okay." And I'm like, "Let's go home now." And he's like, "No, no, no. We're going to have an oral rehab session." And I'm like, ah. I said, "I'm not gonna do anything." And he says, "Yes, you are." And I said, "No, I'm not." But he sat me down, and it was absolutely remarkable to sit there. I had the hearing aid off on this side, the implant on this side, and he's talking to me. And yes, I had difficulty understanding him because it sounded like... It sounded like was a pool of liquid. And it had that artificial lift to it, like it sounded awful. But as I was listening and as I was having success guessing what he was saying, the sound started to become less and less liquidity or morton and started to become more recognizable. So it transformed into chocolate that was poured into a mold. And we would just give it some time to set. And okay, we will pull out one, and it would still be a little liquidy, but there's some form to it. That's the best way I can describe what learning to listen with an implant is like. And when I could hear what my brain was doing to the sound of the implant, and how it was changing just in one hour, I thought, you know what, I'm not gonna take it off. I'm gonna give my brain an opportunity to, and that's what rehab is all about.

- That's awesome. I think in having a professional, that's going to push you and say, no, no, we're gonna do this. In our physical therapy, any kind of therapy, even just a personal trainer who shows up at your house and says, "You're gonna go running, 'cause you told me you want to get more fit." It's hard to make yourself do something that you don't see the immediate results right away, so you give up. But if this person sees your dream and says, "You asked me to help you." And is that what you do with families every day?

- Yes. Yes. I hope so. I really hope so. And with adults, I not only work with babies and young children providing early intervention and their families, but I also work with adults, teenagers and adults of all age, all the way up to the sunshine years. And the purpose is to have someone support them through it because they need a lot of handholding. Even with hearing aids, they need the handholding. And the most wonderful archeologists, they need to spend their time focused on selecting, testing the hearing, making sure that the client understands what they're able to hear, not only what they can't hear, but what they can hear and what they will be able to hear more of with their hearing technology. So you notice how I'm using positive language, works a dream with parents and with clients. This is what your child can hear, and we're going to help them hear these sounds better by doing this or by doing that. And so I do that with adults and it makes such a difference for them because the audiologists are so great. And they're so focused on getting the hearing cache, the hearing technologies appropriately selected, then programmed appropriately. And often where audiologists want to program their clients to where client can't tolerate it at first. Well, we have to, you know, pull it down a bit. And then if that's the case, then we really need someone who knows a lot about oral rehab to know, okay, we got to

keep pushing them, getting the comfort level up, getting the bonding up with the hearing technology, giving them practical real life, kind of explain to them how their daily routines are helping their brain to learn to hear with the hearing technology, along with some exercises, if you want to do that too, but they need to be held through that. They need to be educated through that. And audiologists, unfortunately, just don't have the time to do that, unless they think have this smallest idea of either referring to an auditory or rehab specialist or they develop videos, instructional videos, Pappy videos, educating them about what their hearing loss is, what kind of hearing technology they have, what are the things that they can do to improve their listening skills. And, Dawn, you know, that not too many audiologists do that, you are one of those audiologists. You have a fantastic website with fantastic videos? You know, and the they're so helpful, that's your connection with your clients. And I can't emphasize how important it is to do that. And if you can't do it as an audiologist, then find someone who can, either through a website like yours and/or through a professional like me.

- Exactly, and who wouldn't. Oh my gosh, I, honestly, when I was pregnant with my first child, I would have these dreams that she would be born with a significant hearing loss, and I had already decided she will have a cochlear implant. And if that had happened, I know I would be going to Toronto to go find you to help. Because you not only that you've lived it, you have empathy, but you're also educated. And I know that you're always looking for the next thing. You know that technology changes, technique changes, but you also keep coming back to the foundations. Positive reinforcement is the biggest part, pushing them along so that they get up on those days that they don't want to do the work and the exercises to do it. And then celebrating with them all the wins. Even if it's just little ones. Look at her face, if you guys can see this, like it's right, you can just burst with excitement for them. And it's so good.

- It means the world, it means the world. like the fact that Susan's Scollie was so happy and she cried and she was so excited, Marlene crying. And like, it was such a little bit, but it means the world to us and to have that celebration exactly as you said it, Dawn, is huge, huge.

- I love that you have the word blessed behind you. It makes me so happy, and I am so blessed that you shared your story today. And I know that I should have you on again, or we're gonna have to do a part two, because there's more to your story, right?

- Yeah, yeah.

- That we should probably get into later, but because of time, I am going to cut it off right now. But that doesn't mean that we aren't going to have you back on because you have so many nuggets and some great things that I know everyone will benefit from, but I can't tell you how happy I am that I got to meet you virtually online. And that you shared even a small snippet of your story online, so I knew, oh my goodness, I need to ask her if she could please share with the world of what you know. So where do you work right now?

- I work in a town just outside of Toronto, in what we call Vaughn, Ontario. And I work out of my home office, and I do oral rehabilitation for very young children and for adults, mostly online.



Some of the kids I see, my next client. But that's where I work, and I also have a website company called SoundIntuition. But mostly I'm doing a lot of professional training in how to do rehab for children and for adults as well, That's my passion, so.

- I love it, and you have so much passion. I will definitely be putting in the show notes, all the resources for you. And we will make sure that everyone who would like to reach out to you and contact you in any way can do that. Thank you for sharing, and thank everyone who's listening. Feel free to reach out to Karen and ask her any questions. If you would like to be a part of our podcast here, feel free to reach out, we would love to hear your story too. So I hope you have a wonderful day. Thank you, Karen.

- Thank you, Dawn, I'll see you later. Bye. Bye

- Okay, bye.

- [Narrator] Thank you for joining us on this episode of the "Hearing Wellness Journey Podcast". For more information about what we do and the services we provide, please visit our website at [hearingwellnessjourney.com/podcast](http://hearingwellnessjourney.com/podcast), where you can find more resources based on today's discussion, as well as request to be a member of our hearing wellness journey community on Facebook, that's available for our listeners exclusively, on [hearingwellnessjourney.com/podcast](http://hearingwellnessjourney.com/podcast).