

S2 Ep2

**Katie Colella** [00:00:00] You're listening to *Amplified*, presented by Lurie Children's. Transcripts of this and all episodes can be found at [LurieChildrens.org/amplified](http://LurieChildrens.org/amplified). Last episode, Maria Venalanzo, shared her emotional journey about her son Eduardo, being diagnosed with hearing loss and receiving his cochlear implant. As we know from Katie's story in season one, getting hearing technology is never the end game.

**Katie Farnsworth** [00:00:26] Many families want to know the etiology or cause of their child's hearing loss. Often, the etiology does not change the course of intervention. But parents want to know the "why." Sometimes, take myself, for example. I don't know what caused my hearing loss. Due to my later identification in life, I don't even know when it happened. When Maria became pregnant shortly after Eduardo received his first cochlear implant, she decided to search for answers.

**Maria Venalanzo** [00:00:51] So when I get pregnant from my second child, I was like, I was worried. I was like, so stressed out about about like having another kid with hearing loss. And then I met my husband in Chicago. I didn't know about the whole, his whole history. So, I noticed that he was having some hearing loss, but it wasn't that bad. And then he didn't share anything with me. So I was like, I feel like, "Oh, what's going on?" So at the time when I get pregnant and I start worry about it is when I start like pulling up and asking questions in his family. So his mother told me, "Oh, my kids, they also have this same hearing loss, but they get better." And then I was like, "How that's gonna be possible?" So I questioned those things and they said, in there, it gets better is it gets worse. And I was like, "Oh. So I was like, okay." So when I got pregnant, they said they'd refer me because I had to mention to my doctor about my concerns. And then so she referred me right way to do the specialist. But I find out something really weird that is not this, that you find out that your kids have hearing loss when you're during your pregnancy. So I was like, "Why do I waste all my time for this one? I were like, so stressing on myself? And they, like, worry about it. And then I didn't know nothing. There's nothing that I have to fix." So I like, ugh. So I let it go.

**Katie Farnsworth** [00:02:37] According to the Center of Disease Control and Prevention or CDC, 50 to 60% of babies born with hearing loss involves genetics. If a family chooses, they can undergo genetic testing panels to determine the likelihood of having another child with hearing loss. But like Maria learned, they cannot diagnose hearing loss prenatally. The only way a hearing loss can be diagnosed is after a baby is born, by a licensed audiologist.

**Maria Venalanzo** [00:03:02] I don't know for some reason, but this is my experience. It happened to me. When I got a birth my, my, my, my boy. The only way that I find out is like your pregnancy, you had this history. It was if it runs in the family. Because that's the only way that I find out. Like hearing loss runs in the in the family. They they have to find out.

**Katie Colella** [00:03:28] In your husband's family.

**Maria Venalanzo** [00:03:29] Yes, in my husband's family. They had to find out if it runs in the male or female. And I was like, Oh. So it was like in male, let's say. So it was, I had to find out if I was having a boy or girl. I had to find out the gender. So I was like, okay, what's the difference and the difference is if there's a boy in the front, in the, in the males. The hearing loss runs in the males. The probability my son is going to going to have a hearing loss is high and then he was a girl, it's a lower than the percentage that it's going to have a hearing loss. So that's the only thing. But it's nothing, they can't fix anything. So we're like, okay. So that's that's my experience that I have.

**Katie Colella** [00:04:16] There are numerous genetic markers for hearing loss, but the most common is GJB2 related, also known as Connexin 26. It's estimated that about half of babies born with non syndromic genetic hearing loss is due to a mutation of GJB2. When Esteban was tested for Connexin 26 back in 2010, his results were negative. However, the geneticist noted the reported family history from Eduardo Junior and Esteban's father indicate an autosomal dominant genetic hearing loss. Meaning 50% of Eduardo senior's children have the chance of being born with hearing loss, not just the males.

**Maria Venalanzo** [00:04:54] So when I found out there was a boy, I was like, more worried. And I like, "Oh, man." I was praying and I was like, you know, like, hoping that, that he was going to be fine.

**Katie Colella** [00:05:04] And did, so do you found out before you had...

**Maria Venalanzo** [00:05:07] Yes.

**Katie Colella** [00:05:08] Esteban that...

**Maria Venalanzo** [00:05:09] Yeah..

**Katie Colella** [00:05:10] He was a boy.

**Maria Venalanzo** [00:05:11] He was a boy. I was like six months of my pregnancy, when they told me. So I feel like I know, I trust science sometimes, but I don't trust 100%. I know God always is there for us. But for any reason, they forgot to do the hearing test. I was like, asking all the time, it was nurse it was doctors, it was like, a specialist. The specialists show up that day. So I told him, like, "So you guys did a hearing test?" They told me yes. To my face, they told me, yes, that he passed it. So I was like, so happy. I said, yes, I think everything is good. So, when I went back to for the first appointment after I got Estaban, his pediatrician, I asked him, "Can I see the test?" Because they didn't give it to me. And he say, "Yeah, yeah, I'm going to show it to you. I'll have it for the next appointment." And I was like, "Okay." So for the next appointment, I was like, "I need to see the test." In about that time is because, it was an accident happened in the house. A glass got broke, like a huge glass and he didn't wake up. So I like, I told my husband and then my husband goes "Oh no, no, no, you're gonna go again." I was like, "For real? There's something happening". I said "I can feel

it, I know it." And he was like, "You're not gonna do this again, right?" I was like, "Please listen to me." And said "But they told you, that everything was right." I say, "I know, but I feel like something is not right. And I know he's so little, but I feel like he's not hearing us." At that time, I got Eduardo was scheduled appointment with Miss Beth. Esteban was like two months and some. And then so I mention to her, I worry about this thing and then the pediatrician hasn't given me the test. So she told me schedule an appointment and then I'll make an appointment. And then let's see. And then we going test the hearing. And we're like, okay. So in that time when I was pulling the record and it wasn't the record for a long time, it was like, you know, brand new record. They give it to me, but it was like, copy, on top of another copy. But it wasn't his name. I was like: Wait, this is not my, my baby's name." I was like, okay. So when I, I confront the pediatrician, I say, "Look, this is, this is not right, you guys told me they my baby passed the test and then is not happening. Like this is not his name." And he looking at me like, "Mam, do you have experience in this one? So you think your son is not hearing. You know what to do." And I was like and that's not what I was waiting for. I said, "You know what? You're right. I know what to do. And the first thing, I'm not coming back with my baby. You're not the right doctor that I want to see."

**Katie Colella** [00:08:12] Good for you.

**Maria Venalanzo** [00:08:14] So I walk away. At that time, it wasn't happy. I was, like, so great. Now I don't have a pediatrician. So I was like, ugh. My place I always got support was Lurie. When I talked to Miss Beth, she gave me a list to choose the pediatrician that I went to. And there was one of the, it was, it was the closest one, but it wasn't close to my area. So since then, I've been having the same pediatrician with my kids, and I feel like they always take care of my kids and they always like if I got some issue, they always like, you know, like they're for me, for my kids. But when we find out they did the test, Miss Beth did the test and he didn't pass it. So I look, I look at my husband and he was looking down he was like, "I'm sorry, I didn't believe you." I was like, is, because I was you know, I took some time off when I, I had a baby. So, you know, I got more time. And then, I mean, it's not your fault, you know, like you wasn't there, but at least we know we got experience. We did Eduardo. When Esteban, when we find out that he was having some other heart murmur. I was like, ugh. So it was a heart murmur and there was suspicion about a tumor in his brain. So they couldn't do the surgery for cochlear. When she told me, when we did the MRI, the MRI. So she's the one told me this isn't this is this is the issue that we have now. And I was like, great, so what's going to happen? So she referred me to their neurologist, and to find out. But at that time, she told me, like, you know, these are the situation that we have and these are the situation that we had to work on. So, and this is your options. My option, it was like, to do that surgery with, um, without the magnet.

**Katie Colella** [00:10:31] When Esteban had his MRI, standard for a cochlear implant candidacy evaluation, an abnormality was found. The neurosurgery team now needed to monitor the finding with serial MRIs to make sure it wasn't malignant. Standard cochlear implants rely on an implanted magnet to connect to the external processor worn on the head of the patient. But an internal magnet was no longer an option for

Esteban due to the need for serial imaging and the shadow effect that would be created by the magnet.

**Maria Venalanzo** [00:11:02] So in that way, the, they got to be more scanning. And then, so um, then neurology is going to work on and going to be able to see better in his brain. I was like, because it wasn't going to be anything blocking. So we're like, okay, so but we have to work harder than that because we had to shave the hair in the place that it was supposed to be, put a sticker and put the magnet. I was like, okay. So I think that wasn't that hard. So we're like, okay, so we're going to do this. It was it wasn't easy, but when we are the site to do any. So my husband, he was in – so we got. In that year we got two surgeries. It was one for Esteban, it was another side for Eduardo.

**Katie Farnsworth** [00:11:42] Wow, big year.

**Maria Venalanzo** [00:11:44] Yeah. So, so, now we have, you know, two kids. But now, like it was, I feel like I got a lot of support from my husband because now he knows about the cochlear and he know, that they, they was working on my son.

**Katie Farnsworth** [00:12:00] Maria witnessed her two young boys undergo five surgeries over the course of a few years. Trust in her boy's care team had fueled Maria's faith through this process. So who is this surgeon she had allowed into her confidence?

**Maria Venalanzo** [00:12:13] And then, the Dr. Young, did the double surgery. So that's the reason he got three surgeries, basically like two in one. But he was hearing that the thing he was like hearing and this is what I found out, the more younge that, that you get the cochlear to decide to go for the surgery, is the better because now I compare three years, then 18 months. And it is a lot. But always stand up for them. And then I always told them "You, you, are right, you are normal, you are - it's the same as the other kids doing. Don't you ever feel you're especial because you're not special. You're always going to be especial because you're special, but not because somebody has better than you. Don't go in that way." And not with me, okay because for me, my older kids and my younger kids, they are the same. I came to this country. It wasn't easy. I had to learn a different language. And then because you guys, I had to learn different things. So you see like everybody has the same way. You got some struggle with one thing, just had to work more harder because I feel like everybody is the same, they some people's good for one things and some people good for another things. But it doesn't mean like, you know, you cannot do it. It's only in your head. So you have to keep it up. Esteban got the surgery at young age and his speech is more clearly, and that's for sure. When you decide to do the surgery at a younger age, your brain developmental way in a different way. Because I feel like you got the information, you got all the tools and put all together and it's just a miracle like. You do. But when I'm in, sometimes I know they, they, they as a parent, it's not easy, but I feel like your kid got diagnosed with hearing loss. The more that we work together, there is it's communication between doctors and and you know like the option because we always have options. Like back then we wasn't having options right? But now like is getting better and better and better thank to technology. I

don't I haven't met many of our surgeon doctors, but I feel like she's the best that I ever met. That's one other reason when I they they asked me to volunteering for ParentWise so I always connect with families and with families and share my story. And then it is true like sometimes we don't know and we we need support. And then like I always told my kids, when you don't share things, people don't know, and then when you don't like, share your pain, you feel like you are alone and you're not alone. Because other parents went through the same situation. Some parents got through the same issue as you. And then like support them. I feel like I you I feel like at that time when I wasn't having all of those things in the other hospital. So I feel like there were like more supporting me there. Supporting families because they were sharing a lot, of a lot of stuff, a lot of like experience that we don't had. And I think one not that the, that made me feel like that I was doing the right thing. Because like hearing them, talking to them, asking questions and and getting answers, I feel like like I did the right decision for my kids. Because when they're young, I mean, parents have to decide, you know, they they know, they not decide by themselves. So we had to do either like let them be like that or let them or like make this decision that is going to hurt like a parent, but in the long way is going to benefit them. So I feel like sometimes you get the right support not only from doctors, and and in families. I feel like it is more easy for parents to take on this issue. I don't know about many other parents, but most of the parent that I met, that's one of the biggest concerns, if the cochlear implant is going to work. Oh, if it's going to be good. The first time when I met Dr. Young and today I still remember those words because she told me 5% is the surgery, 10% is the speech therapy, about 80% is your work. And I didn't get it in the in that time because I was like, how is going to be my work? But now I know what she was talking about because it was like driving my kids over here, driving my kids over there talking with them all the time and teach them.

**Dr. Nancy Young** [00:17:36] I'm Dr. Nancy Young, and I am the head of the Section of Otolaryngology within Otolaryngology, and I'm also the medical director of the Department of Audiology and the medical director and founder of the Lurie Children's Cochlear Implant Program.

**Katie Farnsworth** [00:17:53] I'm curious what led you to the field of cochlear implants?

**Dr. Nancy Young** [00:17:55] When I was doing my neurotology fellowship, which is advanced ear surgery, but the patients you deal with are primarily adults. Some kids, primarily adults, though. And cochlear implants had recently been FDA approved for use and adults, were not yet approved for use in children. And in fact, there was a lot of skepticism about whether how effective they would be in children who were born with hearing loss. So it was clear to me that this was an emerging field that was very exciting. And I always had faith that the technology would work in children. And I knew that there, coincidentally, I knew that at about that time there was interest in bringing someone to the Children's Hospital in Chicago, we now call Lurie Children's, to spearhead development of otology in general, including cochlear implant, even though it wasn't yet, the device was not yet on the market. So I knew I knew that this would I really felt this, I felt this had a future. So I thought this was an exciting opportunity. I

don't think too many other people would have at the time would have looked at it that way. But that's what happened.

**Katie Colella** [00:19:39] It's crazy that I think there was a time where people questioned the efficacy of cochlear implants in children, with the culture and the success that we know today.

**Dr. Nancy Young** [00:19:50] Well, cochlear implants from the very beginning have been, were viewed very skeptically for many different reasons. The first device in use in the U.S. was a single channel device, and there was a lot of skepticism that a single channel would provide benefit. Certainly multichannel are better. But what's amazing is there are individuals who are adults who lost their hearing, who got at a device with a single channel, who were able to actually understand speech without visual cues. I actually have videos of that. So so that was very early technology and everyone was skeptical. The other part of that skepticism was that the thinking at the time by neuroscientists was that adults who were the ones getting the implants originally right? That adults did not have enough neuroplasticity to make use of the limited information provided by either a single channel or a multi-channel device. And in fact, Dr. Merzenich, who is by many now considered to be the father of neuroplasticity. He was a young scientist at the time, and he was pulled into a multi channel device development situation at his university. And he has some wonderful stories written about this because he, based on the thinking of the time, he just was like these surgeons are you know, they don't know what they're doing. And this doesn't make sense because this is going to require too much neuroplasticity and adults don't have it. And then he writes about how he was present at the activation of an adult who lost their hearing, who got this new multi-channel device. And he could understand words right away. And it's like a light bulb went off on his head. He realized that what he had learned about neuroplasticity was incorrect and that this was an area that he needed to research. And he didn't stay in the implant field in the long term. He really did a lot of research looking at adult brain neuroplasticity in general. So there was skepticism from the scientists. And then, of course, there were people who felt that the deaf shouldn't hear. So there was controversy from those quarters. And that made it challenging for people doing implants in the early days because it just made optimism and for benefit and acceptance more difficult.

**Katie Colella** [00:22:57] We all learn about cochlear implant history and I like hearing it from you though. So I feel like whoever taught it to me at some point in undergrad or grad school hasn't been as engrossed in the field as as you are. So I love hearing what it's like from someone who was really in the trenches before it was so widely accepted.

**Dr. Nancy Young** [00:23:19] Yeah, it was. It was very interesting and it was very interesting. I think that in the early days, a lot of teachers didn't want it and didn't want to support it. And I think that's really changed.

**Katie Farnsworth** [00:23:40] Yes. So the Cochlear implant program was founded at formerly Children's Memorial back in 1991, I believe.

**Dr. Nancy Young** [00:23:49] We worked on it for quite a while to set it up, but that in 1991 is when the first child at Children's Memorial was implanted and that was actually the first child to receive a cochlear implant in the city of Chicago. Prior to that, there were a few kids implanted, but they had, but not in Chicago. They had to leave because there was no pediatric implant center in Chicago until we started one.

**Katie Farnsworth** [00:24:04] That's crazy.

**Katie Colella** [00:24:05] I didn't know that.

**Dr. Nancy Young** [00:24:07] Yeah, well, that's 1991 was when the first multi-channel device was approved for use in children. '85 was when the first multi-channel device was approved for use in adults. And the single channel device never got FDA approval.

**Katie Colella** [00:24:22] 91. That's the year you were born.

**Katie Farnsworth** [00:24:21] Actually was born in 88. For those keeping score at home.

**Katie Colella** [00:24:24] Oh that's right, I'm older, so I don't know, like, just to use some reference of your journey, but nevermind.

**Katie Farnsworth** [00:24:30] So, so, then fast forward kind of at the end, I believe, of 2019, Lurie Children's celebrated the 2000th surgery, you know, cochlear implant surgery. I know we've talked a little bit about advancements just from single to multi-channel. What do you feel like? What are kind of the biggest advancements that stick out in your mind? You know, over the course of of this program?

**Dr. Nancy Young** [00:24:54] Well, there are, there are many advances and they're important for different reasons. One, probably from a hearing standpoint, one of the most important and I don't know what year this happened, but Blake Wilson developed advances in software which are used in all of the implant systems. And that from, I think, laid the basis for major improvement in how much information implant recipients, both adults and children receive. I mean, that that was huge. Since then, well, I don't know, but since the beginning, shall I say, I mean, of course there's the change in size of the processor. That's huge. I mean, it used to be a big box and you'd have to wear it on your belt. And now we have the equivalent of a behind the ear hearing aid or what I call a button processor where there's nothing sitting on the ear that the entire device is like a disc that sits on the side of the head. So I think that's really huge. The internal device is thinner as well, which is which is nice. But I really think changes in the external is what makes the biggest difference cosmetically, because the surgeons could we could deal with the size issue, although it's nice that it's smaller. I think from a patient perspective, I think for older patients, I mean older for teenagers and adults especially, I think some of the newer features that allow for streaming that sort of so sort of software, I think really is really appreciated by patients kind of life changing. Yeah.

**Katie Colella** [00:26:50] Even in the hearing aids, they love it.

**Dr. Nancy Young** [00:26:55] And I think that's been huge. The other thing is magnet design. When I started, there have always been magnets or not always. There was an early cochlear implant system that had a post that stuck out through the skin. It never got FDA approval. It was great for research purposes, but you don't want to post sticking out of skin on the side of your head for both cosmetic reasons. I think because of irritation to the skin around it. That, look, that was the early BAHA, too.

**Katie Colella** [00:27:31] Yes, I was.

**Dr. Nancy Young** [00:27:41] It was a post. All right.

**Katie Colella** [00:27:48] The abutment. Mm hmm. Mm hmm.

**Dr. Nancy Young** [00:27:50] But pretty quickly, it evolved to no post and a magnet. The concept of the internal and external magnets allowing retention of the external coil that allows the system to connect and work. You know, that was really developed for cochlear implants. Didn't exist before cochlear implants. And initially, the magnet could not be removed. And back then, MRI was really not very common, and it was only done of the brain. And most medical centers didn't have one. And major, major medical centers did. But that was about it. So MRI technology has dramatically changed, improved and become quite common and is now used for diagnosis and management of diseases throughout the entire body. So the problem is, if you have a cochlear implant and there's a magnet in it, that can create issues with obtaining good images of the brain, because there's artifact, because an MRI is using magnetic fields to generate an image and putting a magnet in that magnetic field causes artifact. So initially, the devices were not FDA approved for use in an MRI machine. But I, I mean, I still had patients get MRIs even way back when the magnets were not removable. I wasn't going to, you know, take out the device to get an MRI done. If I thought there was a chance we could get a good image otherwise. So working with our radiology colleagues, we were able to, we had a few patients we were able to get MRIs done successfully. And now that's not always possible, depending on if you need to image the brain, what part of the brain is it going to be where the artifact is? The other thing is, I think in the early days there was concern about just going into an MRI, forgetting about the artifact, just even being inside of an MRI with a cochlear implant. Now that is very much evolved. So it became clear over time that not having access to an MRI was a problem. So there were different approaches taken. But the more common approach was several of the manufacturers created a removable magnet and that sounded good. And we certainly did have patients that we did remove it at times. But once again, nobody wants a surgery. In fact, two: one to take it out and want to put it back in. They are not major surgeries, but no one wants additional surgeries and anesthesia. So at Lurie, we were as long as we thought we could get decent images. We had a system for getting MRI in patients who had these removable magnets without removing the magnet. We went through that period of evolution, and we've actually published on that our success. And then I think a really big advance was one of the manufacturers developed what's called a diametric magnet. So the prior magnets were axial, so the forces were perpendicular to the head, meaning the magnet wanted to exit. It was



pulled out. Right. So the diametric magnet, when you placed it in a magnetic field, it spins. So they made it so that it would like spin in this little container. So it really didn't put any forces that you could feel on the patient. And it's it was still a removable design because you might want to remove it if you really needed to get a picture of the brain in an area where there'd be artifact. But honestly, we've never had to remove that type of magnet, um fortunately. And just getting MRI's done now is very easy if you have that type of magnet. We used to have to put patients either sedate them or put them under anesthesia because they would feel this sensation and they would freak out. And this wasn't just true of children, but adults would get very anxious because they'd feel something in their head pushing out. So we always sedated the kids, even though they were an age where you normally wouldn't have had to for an MRI when it was the axial magnet that was left inside. But with the diametric, it was great. You know, the kids could just get MRIs and they have these other MRIs. You may not know about this, but they have these, there's different nicknames for them. They have these really, really quick MRI's. They don't give you a lot of detail, but they use them to image the size of the ventricles. So kids with shunts, where they're just like, Oh, is there a shunt malformation? Are the ventricles getting larger? So you just need a real super quick study that takes a few minutes. So this quick study was designed so that you could do it even on little kids without sedation because these studies are so short. So those were never available to our implant kids before. So now our kids if they need it can also get those quick studies. So if they happen to have a shunt and a cochlear implant or, you know, or some other problem with hydrocephalus or enlargement of the ventricles needs to be ruled out, it can be done. So it's great. There are far fewer kids needing sedation and anesthesia for imaging studies at Lurie.

**Katie Colella** [00:33:45] And I think that brings us this is a good segway to talk specifically about Esteban, who, you know, he was implanted in the early 2000s when the program was established, but still relatively young. And he was a unique case at the time, as we understand.

**Dr. Nancy Young** [00:34:04] Yeah, there were reasons that to do with follow up imaging that were recommended that his initial implantation in one ear did not include the magnet so that he could be followed by the I believe it was the neurosurgical service. Fortunately, we got to the point where that issue was resolved and serial imaging was no longer necessary. So at that point, we were able to implant his second ear so he could be a bilateral implant user. And we actually gave him a new implant for his first ear that contained a magnet. So that certainly helps with retention, which is really important because as everyone on the Lurie team is always trying to remind people, how long you use the device every day is really, really important. There's a wonderful phrase that another group came up with that goes like this: eyes open, ears on. I think eyes open, ears on is a great concept. And I think keep in mind that, you know, the rest of us, we non implanted people, our ears are on when our eyes are closed too so we we have the opportunity to hear 24/7, not people with implants. So while their eyes are open when they are awake, they need to be using them, especially if they need to learn how to listen and learn how to talk. There's a lot the implant center can do, but if if parents

aren't ensuring that young children are wearing their device during waking hours, then they are not going to achieve their full potential. The kids.

**Katie Colella** [00:36:02] It's true, and I think this is such a collaborative field, and it's not just among the medical professionals, it's with the family, because at the end of the day, the people that need to be the most invested are the parents and the caregivers or the grandparents or whomever is keeping these devices on the child.

**Dr. Nancy Young** [00:36:22] Yeah, yeah. Fortunately, as the kids get older, you know, once they typically bond to their device and start taking charge of it. And well, sometimes they're the ones driving the bus. Yeah.

**Katie Colella** [00:36:36] Which is great when they do that. It's great to see that transition.

**Dr. Nancy Young** [00:36:41] Yeah. I mean it doesn't always happen, especially if there isn't that habit of always using it.

**Katie Farnsworth** [00:36:48] Well, admittedly, it's a very nerve wracking experience, even as a, you know, an audiologist who has had a hearing loss my whole life and working with children who have cochlear implants and seeing how much success they had, I mean, surgery day for me, I was a mess. I mean, I was so nervous and I don't know if it was part of me was mourning, having worn hearing aids and this was going to be such a transition, I don't know. But I was I was pretty nervous going into surgery, to be totally honest.

**Dr. Nancy Young** [00:37:19] Yeah, There's so many different reasons people are nervous. You just, it's incredible. It's so many more than you could ever imagine.

**Katie Farnsworth** [00:37:28] Yeah.

**Dr. Nancy Young** [00:37:29] And there are so many reasons. I mean, so here's an early in the field story, AG Bell, which is an organization that, you know, promotes listening and spoken language. So when cochlear implants were new, you know, 30 years ago, they were certainly very supportive of anything that would support listening and spoken language. But a lot of their adult members with hearing loss were people who, through use of hearing aids and therapy, had developed the ability to talk. And they were very, very proud of that.

**Katie Colella** [00:38:03] Do you think they used a lot of speech reading, too?

**Dr. Nancy Young** [00:38:05] Some of them, of course, did. Not all everybody's different. But for that group. Oh, and there's an interesting corollary with professionals. So with that group of patients, some of them felt that to get an implant was somehow like they were a failure because they should be able to do this with a hearing aid because some people could. And the same thing with auditory verbal therapists. The local auditory

verbal therapists we worked with immediately embraced this technology. They saw that it would make things easier for their patients. But there were others elsewhere in the country whose initial reaction was, Well, I'm such a great therapist that my patients don't need this. So they sort of looked at the child getting an implant as somehow a failure. Like if they were truly like the most amazing therapist, as they thought they were, then, then their patients would need this, which is really sort of interesting, given what their goals are of what they want to do. You know, we want our, we want our patients to succeed, but we also don't want to give them the the hardest road. We want to give them the option of, you know, an easier road. Right?

**Katie Colella** [00:39:21] Yeah. Path of least resistance, right? Yeah. Yeah.

**Katie Farnsworth** [00:39:24] One thing that my dad actually brought up in season one was when I was first identified probably in 1991. That's probably where that comes in.

**Katie Colella** [00:39:32] That's probably where that comes from..

**Katie Farnsworth** [00:39:34] Yes. So when I was first identified, you know, the Internet was in its infancy and there was no real, like way to connect and to hop online and find out about hearing loss, about, you know, rehabilitation, about any other support groups. Do you find that that has also changed, you know, the kind of families, you know, that the information that maybe parents come in with, like the amount of knowledge that they know when they first meet you versus a few decades ago? Do you feel like it kind of, you know, depends?

**Dr. Nancy Young** [00:40:09] I think I think it depends pretty early on. I think what happened as implants started taking off in Chicago, I think pretty strong networks developed. And so I think a lot of patients would get information from other patients even before social media. And then, of course, we had. But, you know, now we have ParentWise, which is a system to maintain privacy but still allow parents to connect with other parents. But before then it was more informal because they didn't have all these rules, and parents would be like, "Hey, just give this people you think our name and number." So we were doing that when that was permissible. Like way long, long time ago. And so, yes, information is more accessible now, but there's also and sometimes there's too much information. People look at information that doesn't apply to them, stories that don't apply to them. The other thing that happens is there's misinformation out there, either either information that is just incorrect or information that's actually being put out there because there's an agenda against having people to have a cochlear implant. So sometimes so it can cut both ways. And I think the other problem is even if there's reasonably good information out there, I think for parents of a child that was born deaf or recently lost their hearing, I think it's very they're very overwhelmed. It's very emotional for some people. I think it is very hard to read something that you're not intimately familiar with already and really understand it. I think it's very difficult. So one of the things I think we we try to do on the team and we often do well with there is always room for improvement, we often do well, is try to reinforce certain messages. I think it helps for people to hear the important information more than once and

sometimes from different people. Sometimes one person will have sort of the way to frame it, and that makes the most sense to that parent. And it's and it's it's not necessarily the physician that that has that that that ability to frame it the best and sometimes it may not be what's being said, but who's saying it. Sometimes the parent will bond with a particular person on the team. They just feel the most comfortable with that person. And when they say it, a light bulb gets on. Even though the same thing might have been said by other people.

**Katie Farnsworth** [00:42:52] I think that's a really wonderful way of saying it, because I think I've definitely seen that in my practice too, where I feel like I've just been really thinking, I've been getting my message across, and then perhaps I'm getting a message from a speech therapist that maybe there is still confusion about what's being said. And I think, you know, again, to give that consistent message is so crucial and there are so many different people that these patients meet along the way, especially is undergoing kind of the candidacy process between the audiologist and social workers and educational liaison and therapists and, you know, ultimately surgeons as well. To have that consistent message, I think is wonderful.

**Dr. Nancy Young** [00:43:35] The other thing I think and I've gotten better as I've gotten older, is to ask some open ended questions, find out what people's goals are. Sometimes when people say things and it strikes you as funny, as off, as confusing, is to stop. And it's hard for us to stop because we've got our thing we really want to say, but to stop and to say, "Well, why are you asking that? Is there something you're concerned about?" And so you're talking about X, but they may be going down a rabbit hole about something that you're completely unaware of and would never have occurred to you.

**Katie Farnsworth** [00:44:15] One thing that Beth actually said as well was rather than just saying, do you have any questions, it's what questions do you have? So it really and and giving that true pause, right. Like allowing a family to feel like it's okay to have questions and, you know, questions are welcome.

**Katie Colella** [00:44:35] And expected.

**Katie Farnsworth** [00:44:36] Yeah, and expected because this especially when we're talking about a cochlear implant I mean, I think it's I think, of course there are questions, right? I mean about some point of this process. So what questions do you have? I felt like that was wonderful.

**Katie Colella** [00:44:53] Well, this has been wonderful.

**Dr. Nancy Young** [00:44:56] Always a pleasure. And it's wonderful to have my two questioners be audiologists, my favorite people.

**Katie Colella** [00:45:05] All right.

**Katie Colella** [00:45:17] This is 2 for 2, two Katie's, two questions. Katie Farnsworth, you have never undergone genetic testing for your hearing loss. Have you ever thought about doing it?

**Katie Farnsworth** [00:45:31] Yeah. It was a big topic of conversation, actually, when I was pregnant with my oldest daughter, Nora. If we were going to undergo genetic testing for her and, you know, at the same time, I was thinking a lot about, you know, what the implications of that might look like. You know, I think for kind of we touched a bit on this in season one where if there was a genetic component to my hearing loss, that was not going to deter me and Chris to have children. And if anything, because of my profession, if our children were to have a hearing loss, they were going to you know, we were going to be able to figure this out and and really get them the support that they needed. I think also because I didn't have any other comorbidities that, you know, for me it wasn't something where I felt like a sense of urgency to really undergo genetic testing.

**Katie Colella** [00:46:31] Okay. Yeah. And I think there's a lot more panels now, too, from when you were a kid.

**Katie Farnsworth** [00:46:37] Mm hmm.

**Katie Colella** [00:46:37] I think it used to just be. Do you have Connexin 26 or do you not have that? And now the panels have expanded quite a bit because there we know now more that there is so much is genetic. When it comes to childhood hearing loss.

**Katie Farnsworth** [00:46:52] Yeah, I think there's there's so much more knowledge now than there was 30 years ago when my parents discovered my hearing loss. And at the time, I would I wouldn't be surprised if it wasn't really as much of a conversation as it is now given, you know, just advancements in genetic testing and different things that they may be looking for. Trying to think of a good question for you. You really you got an easy one.

**Katie Colella** [00:47:18] I did. Oh, man. I get the softball. I get the softball.

**Katie Farnsworth** [00:47:24] Okay. I'm wondering about. So my question to you as part of my cochlear implant evaluation process, I underwent an MRI to look at the structures of my inner ear. And I'm wondering if you would like to share your experience with receiving undergoing an MRI?

**Katie Colella** [00:47:44] Sure. I actually had to have an MRI because I had a sudden hearing loss. It was in 2017 or 2018. I had a sudden hearing loss, started with a sudden tinnitus in my left ear, and then two days later I woke up and it was a Saturday. And I could tell I just was not hearing out of that left ear. Went to work on Monday and fortunately, you know, had access to a sound booth. And so our extern at the time Zoe tested my hearing and I had a severe, rising, a moderately severe sensorineural hearing loss. And I was fortunate. I called in Northwestern Medicine and they walked me in that

day because a sudden hearing loss is something that you should see an ENT urgently. And I ended up getting steroid injections into my middle ear, and it worked. My hearing did resolve, which that's the also was a such a bizarre experience because it came back like it almost sound like when you had one of those old radios that had the dial, that was the power and the volume dial all in one. And it would you would turn it on and it would softly crackle and would slowly go louder and louder. That sort of felt like in my ear. So but then they still recommended an MRI because it was this sudden thing, and they wanted to make sure that there wasn't any type of, you know, benign mass or anything in there. So and it was and it was clean. But, you know, these when you hear about someone as young as Esteban having to go through serial MRI's, that's quite an experience because they're not a calm experience. I mean, even if you have a hint of claustrophobia, it's tough. You mean, you know, you got to go headfirst into that little chamber and it's this booming experience, you know, it's hard to relax all that booming. I don't know how much you heard the booming.

**Katie Farnsworth** [00:49:48] I was going to say there was minimal boom.

**Katie Colella** [00:49:51] Okay. I guess that is the upside of going in with a significant hearing loss. But then you're not you're not aware. You can't hear the technician talking to you. Right. Like, at least I had the technician who was able to cue me, let me know. I'm things are kind of wrapping up how much longer I have, but you probably don't have any of that available then to you.

**Katie Farnsworth** [00:50:17] I did not. You know, and I think it's interesting because so many of our patients are so little when they have MRIs. And, you know, you have to be so still when you're in that chamber that so many of our patients do undergo sedation to be able to have the MRI completed and have really clean looking images. So I think as an adult, it's a very different experience than, you know, somebody who potentially would be an Esteban's age undergoing serial MRI's. My guess would be that he would have been put to sleep for each of those each of those evaluations. But, yes, I mean, I have heard that MRI machines are extremely loud and that is not something that I obviously experienced.

**Katie Colella** [00:51:04] Yeah, it's a booming it it's pretty loud. But I'm glad I you know, I'm glad I did it so I could have that peace of mind. But yeah, I give all these anyone in the field, the radiology credit of helping calm these patients and especially children and then their poor parents waiting for, waiting during it. So, yeah, that was quite an experience. It's funny, I kind of forget about that one I that I'm like, "Oh, yeah, I had that sudden hearing loss." And it's funny because on our team there are a couple people who have and it's just funny that in a group of audiologists, how many of us have that's happened to.

**Katie Farnsworth** [00:51:46] There's something in the water obviously.

**Katie Colella** [00:51:48] Yeah, right. Not the Lurie water. It's very clean. No, but I guess we can. But I guess we should take this opportunity to let people know if you do ever

wake up with a sudden hearing loss, significant hearing loss, that is not something to take lightly. You you should, you know, contact your primary care physician and get yourself to an otolaryngologist because it is possible that they can provide a treatment that will resolve it.

**Katie Farnsworth** [00:52:18] Yeah. And even before, also in your case, you know, you had that significant ringing in your ear that preceded the hearing loss as well. So I think also if you're experiencing other symptoms such as that ringing or fullness in your ear, that's not necessarily related to an ear infection or congestion, something like that, I think that's something that should be addressed quickly and not just ignored.

**Katie Colella** [00:52:40] Yeah, absolutely.

**Katie Farnsworth** [00:52:42] Stay tuned for episode three, where we dive into really language as a whole.

**Katie Colella** [00:52:49] Yeah, no, that one. I'm excited because it's a trilingual family. Stay tuned. Thanks for listening.

**Katie Farnsworth** [00:52:55] Amplified, presented by Lurie Children's, is co-hosted by

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