

S2 Ep1

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. Welcome back to *Amplified* presented by Lurie Children's. The podcast about growing up with hearing loss. My name is Katie Colella, a pediatric audiologist at the Anne and Robert H. Lurie Children's Hospital of Chicago. Last season we followed fellow pediatric audiologist Dr. Katie Farnsworth journey from her hearing loss diagnosis at two and a half years old to present day. Katie was such a natural storyteller during season one that it only made sense to make her a permanent part of the show as a co-host. Now the podcast about growing up with hearing loss will have a host that actually grew up with hearing loss.

Katie Farnsworth [00:00:48] That's right. I will be joining Katie Co as co-host this season. Together, we search for a new family to interview with our Lurie Children's ParentWISE program. ParentWISE pairs caregivers whose children have received new diagnoses or recommended interventions to volunteer families with similar experiences. It's an opportunity for parents and caregivers to get answers from others who have walked the walk. That's how we found the Venalonzo family. Maria Venalonzo has been an active and passionate member of ParentWISE for years. She has a unique perspective of raising not one but two children with hearing loss, both with different communication styles. We first met Maria in person after weeks of corresponding via email and phone. It wasn't until we started talking that Maria realized I was the same Katie from season one.

Maria Venalonzo [00:01:30] I never made the connection. Wow. That's. That's all.

Katie Farnsworth [00:01:35] And so thank you so much for taking the time to share your story, because I think so many listeners want to hear about another perspective. The first season of *Amplified* was about a particular family back from the early nineties, and so it's nice to hear a couple decades later what it was like. And also, you know, all of the navigation that you guys had to do, you know, for both boys.

Maria Venalonzo [00:02:05] Boy, its a lot of work. It is. First of all, I got once or when like I wasn't ready for that. So I didn't know in the beginning, I didn't know was that mainly when they didn't pass that the hearing test. When the doctors told me, "Oh, he didn't pass the hearing test." and I was like, "Oh, okay, so what does that mean?" So they they told me, "Oh, you had to come back like two weeks later to do that again." And then we did go back and then so they didn't pass it and they were like, "Oh." So for me it was like nothing, because I didn't hear him. I didn't see him cry. I didn't feel like the he was like, in pain. So for me, we're like, okay. So when, I was working at the time, so I had to enroll him in a daycare. That the daycare teacher had a hard time to to get the attention from him. So I like, "Oh, it's okay, he's just a baby." And then I didn't realize how bad he was. So like he was, I think like 11 months when we start to worry about it, because that teacher from the daycare, she was refusing to take care of him. And I was like, "Why?" He say, "It's because he's not getting attention from me. Everything, when I tried to talk to him, he was like not responding. So it's getting harder and harder for me to, you know, to give directions." And I was like, "Oh, but he's not doing that like that with me. He's okay." And the reason is because I always carry him. I was like, hugging him. I was like, giving attention to him. And he was the only baby. And I was like, oh. We got two older kids with hearing that normal. So it was everything was like playing around with them. So but we noticed that he, he wasn't speaking, he wasn't doing any sounds. And I was like, oh, maybe, it's, maybe this is the reason the teacher was worried about it. So but then it's not. So after that, like one of the teachers I mentioned to me about the hearing aids, and then I

said, "What is that?" They said, "That's gonna support him to hear." And I was like, "Oh." And what I can give is that you had to take him to the pediatrician and he's going to refer you to the specialist. And I was like, I was too much work. Like, okay. But I did it. So for any reason, I did it. So we're, like, curious to find out about, like, what's going on. So when they send me to the specialist, they've made that ear molds.

Katie Colella [00:04:53] Ear molds?

Maria Venalanzo [00:04:53] Yeah. And then they did it right away, and then they, they give him the hearing aids. But it wasn't enough for him. So the specialist, the audiologist told me they, "Oh, the only way we can fix it is to get the surgery." And I was like, there was like something more bigger than I thought. I was like, "What are you talking about? Why my baby going to have surgery, he's so little." And I was like, "Oh, no, I don't want my baby to hurt. And then especially in the head. So no, no, no way is no way they are gonna do it." So I let the time go. But it was like something inside of me. They were like, wondering what are going to be his life without hearing? How it's going to be his life without talking? So I like so he was like something like it wasn't like right. So I start getting more information and find out about it. So we made the appointment for the MRI, so he got all the tests he was about like to happen it. And then I was like, "No, I feel like something is not right." So when I shared the story with my with my coworker, she told me, I said, "You know what is a good hospital?" Because the beginning, the first plan, the first time, it wasn't Lurie. So I was like, "No, I don't feel right. Something is not right." When I told when I ask more questions about like, how is it going to be the situation, what is the process, and then what's going to happen up there to the cochlear. And she never mentioned to me about speech therapy and I didn't know about this. So it just feels like it was a miscommunication between. And then she didn't explain me everything, like how was she supposed to. And then so my, my coworker mentioned to me about the Children Memorial now that time it was Children's Memorial and not Lurie. So they she mentioned me that and I say that's the right place to go and take your baby. When I met Miss Beth, so she explained everything to me. And at that time it was like the speech therapist, oh, and they referred him like right away to do speech therapy. And I was like, "Oh, so I feel like I'm in the right place now, and I feel comfortable and I feel like, like a connection." Because every time when I was having a question, so I was having an answer and then it was like a lot of support and there was like a lot of help. So when they mentioned me and then we got the meeting or your son, he needs the surgery, at that time it was only candidate for one side. When I say so, I was like, okay, so what's going to happen? He said, "Well, we this is the process that we're going to do for the surgery. And then now he's gonna continue to the speech therapy." And I was like, okay, so, but my husband and his side was then like he was like, so negative about it. So I like, oh so, now I had to work double with this. So at that time it was like families getting together, like family sharing their stories and be and people with cochlear implant like talking.

Katie Colella [00:08:14] Maria is referring to Sound Experience. A Lurie Children's program started over 20 years ago by audiologist Dr. Joy Ringger and parent of a child with hearing loss, Sally Wolford. Events are held roughly every other month to build community for local families of children with any type of hearing, loss, hearing device or communication modality.

Maria Venalanzo [00:08:36] I'm like so emotional, I like, "Oh my, oh my God, my son is going to be like that." So like one day he's going to be like that. I talk to my husband, I say, "Look, this is what are we gonna do." And then he said, "But I don't want it." I was like, "I know you don't want it, but it's going to be good for him. And then like, "It's going to hurt

us. But just think about it. One day you're not going to be there for him. And then he has to, you know, he has to go out, he has to go to college, he has to go to school, and then you're not going to be with him 24/7, so we need this." He was like, "I don't know. I usually don't feel like that we have to do it." I say "We had to do it and we're going to do it." And I was like, "I already decide to do it with or without you do the decision, because I feel like this is the best that we can do for him."

Katie Colella [00:09:29] That must have been a really hard conversation to have.

Maria Venalanzo [00:09:31] Yeah.

Katie Colella [00:09:32] With your partner?

Maria Venalanzo [00:09:33] Yeah, it was really hard. So I like, so he wasn't like 100% sure that was going to work because he... one day he was like, "How about it doesn't work for him?" I was like, "Just think positive and all those good things going to come up, but you keep thinking in that way, so that's not going to work." So we start already. We start the process and then we start working and preparation. So when the happened, the surgery happened, so we were together there. It was a pain, you know, in between, because seeing your baby there. So it's not fun. We left the hospital the same day, so he was like, "Let us take care of that." I took some time off from my work in the night. I think it was two weeks at that time. And then so the third week when we were supposed to be go back. So we went back. He was so emotional, that day. I remember when they they, they connect the cochlear to him and he was, he was amazing like, let's see him like calling his calling his name. And then he just turned around like, "Oh my God." He was like, it was a miracle then. So I saw my baby for the first time hearing me. And then I was like, he was like, it was so, so, so, like, emotional that day. And then so I said, "Yes, I'm Mommy, I'm your Mommy." And then and then he turned around with my husband, he was like, like looking at him "I said that's your Poppy." And then for the first time hearing his voice, he was like, it was so, like, so good.

Katie Farnsworth [00:11:22] When a cochlear implant is activated or turned on for the first time in children who have heard little to no sound in their lives, the responses can vary. In my experience, some kids demonstrate the great AHA YouTube moment and others do not react at all. After a long emotional journey, it was heartwarming to hear Maria witness Eduardo's undeniable detection of her voice.

Maria Venalanzo [00:11:43] And then after that, like we start working in the speech therapy. So he's he's very smart. He's so smart the boy. And then so every time we were taking turns, my husband was attending to some therapies and I was attending another therapy because we get involved. It was another community program that we involved and they were teaching him sign language and there was a Lurie giving a speech therapy. So and then after that it was a school involved too. So it was like, okay, we had to like cut a little bit somewhere with it because in our schedule it was like, so time. And then so when we when we decide to enroll in the school, it was also like a frustration there because it was at the time start school and he was a surgery. So it wasn't enough time to to let him allowed to like to share that like this situation he was in between. So the school day wasn't like want to deal with it. And they they sent him to only sign language school. So and then in the beginning it was like hard because I, I like stand up and I say "I don't want my son be in only sign language for school because it's not point for me to get the cochlear implant unless in the day not that they he only want to learn sign language." I say "That's in all their program they it has to be." So they told me they was a Total Communication

program but he wasn't fitting in the in the right way because he wasn't speaking anything, any language, not even Spanish not in English. And then he you start learning like some words and then he didn't fit. And I was like, "Oh, I don't know. I don't know about this one." I don't have a lot of experience because I didn't I didn't know. It was my first baby with hearing loss. So I like, okay, so what what do I have to do? So I shared this with Miss Beth and then she told me, "Oh, you know, is a person if they see that's the that was her name."

Katie Farnsworth [00:14:11] Maria is referring to Stacie Simic, the former education liaison for the cochlear implant program at that time.

Maria Venalanzo [00:14:17] And that was supporting the schools. And I was like, okay, so she she's the right person to talk to. So I, I talked to her and then I explain her was the situation. So and then I told them I want him in program like Total Communication. So she worked with the CPS and then CPS has a little bit like demand that they they sometimes, I feel like they didn't want to deal with them. But I told and I "We don't get the opportunity, you'll never know." Because things happen all the time but if they hear and are ready you know like, we just have to work a little bit more harder. But it did happen. So he was in Total Communication and that helps a lot.

Katie Farnsworth [00:15:10] I would love to ask some questions about at the beginning after he was diagnosed with his hearing loss. So I know you mentioned that his day care teacher was also expressing some concerns to you. Did that then lead you guys to do some follow up testing with his hearing loss? I know you mentioned he went to get some ear molds and hearing aids. Did he have another hearing test at that time?

Maria Venalanzo [00:15:34] Yeah. When, when we the pediatrician refer him to the specialist, they did the the hearing test again. And then so, they told us that his hearing loss, it was like very profound. He was hearing at like you were hearing like 100%. He was hearing like 25% or less in there. So he was hearing they say they were, hearing like like very, very and loud noises like a blender. So there was the blender that was always like using, right? But other than that, they said they wasn't hearing like us, in especially like we talked like. So he couldn't be able to hear. So I was like, okay, so that was the diagnostic that they gave us to us. So when we went to Lurie, they did the same tests and all that. So but we were already having experience from one hospital and to the other one when we was already know what was going to be the situation. We only waiting for to tell us that he needs to speech. We wasn't ready for for the surgery because in our head we was like wondering like there was miracle is going to happen tell us that like everything that has been done was like wrong. So but when we found out they it was the same diagnostic. So I like, okay, so and then we were we start working on. So he was like around 16 months when we really start working. So the I think that um, the time that there has to be preparation for that surgery or so, like he was like, eight months, something like that. So he got the surgery when he was two days after he turned three years. It was December 19. His birthday is December 16. So he's he got the cochlear. And then three weeks later they did the activation. So and then when he start hearing and it was like really, really nice. After that, like, you know, like he went, he got implanted and December 19, that's a six. So he was already three. And then we enrolled him in in school in September. He got his surgery in December. So at that time it was like February. They don't want to deal with this. So in there's when we start like working again with the schools. So but he get it, he get them the program it was the school he was in Hyde Park. So he was, we live in the in West Chicago, in the schools in East Chicago. So he was driving from home to to that school. And there was like speech therapy. So we was like pulling out from, from, from

school or we were dropping out play. So that was like the situation there. It was only one kid, so it was more easy.

Katie Colella [00:18:51] Over the course of this season, Maria will share more about how she navigated the educational system and advocated to get her children appropriate services. But despite her boys attending multiple schools and working with several therapist over the years, one person on her care team has remained constant after all these years.

Maria Venalanzo [00:19:10] When when he got that, every time where he updated his devices is something different with him, I don't. I don't understand. Sometimes I don't get it, but it's a little bit more when when we switch from one one thing to another thing. They traveled to Mexico before the pandemic and there was something really weird. When he came back, he was having like some issue with his one of his devices. And then I so later on it got fixed by itself. I don't know, like maybe I can I say Miss Beth has to do something with this. But yeah. So it was like, okay, so it go away.

Katie Colella [00:19:55] That constant has been her audiologist and our colleague, Dr. Beth Tournis.

Maria Venalanzo [00:20:01] And then I was like, so worried about like, "Oh, maybe it's going to start working or it's going to get another surgery." But nothing that, everything gets better. And then now it's just not there anymore so.

Katie Farnsworth [00:20:12] Yeah. Cochlear implants are just such an interesting, interesting thing, right? And I think sometimes you can think, "Oh, is it equipment related, Is it hearing related?" And I think it takes a lot of troubleshooting and a lot of support from your audiologist, from the hearing therapist, from the speech therapist. I feel like you've mentioned a lot of really cool people that have helped support you, you know, to help both boys learn to hear and learn to listen. Do you feel like, I think you mentioned this too, kind of your you when you first met Beth, Miss Beth. You know, what was that like? Cause I know you came to Lurie more as a second opinion to kind of be able to move forward with a cochlear implant for Eduardo, if that's what he needed. What was that like? What was it like meeting her for the first time? Do you remember meeting her?

Maria Venalanzo [00:21:01] Yeah, actually it was like really cool because she was like a doll. She's skinny doll, but I feel like.

Katie Colella [00:21:11] She's tiny.

Maria Venalanzo [00:21:12] Yeah, she really is. She's beautiful. I mean, like, I feel like we got a really good connection because she gave me that she gave me all the answers that about all the questions that I had. Even like for me was like, dumb question. It wasn't dumb for her. So she always like, "Oh, no, Maria, this is the way it works." And this is always like, you know, it made me feel like a family now. Like I always feel like a family and know her for since they were like my whole life. But and there's a few people that I always feel in that way.

Beth Tournis [00:21:53] I'm Dr. Beth Tournis. I have been working at Lurie Children's Hospital, which was formerly Children's Memorial Hospital since the early 2000s when I graduated. And I have been working on the cochlear implant team since 2003. So for 20 years. And before I worked on the implant team, I mainly did ABRs and worked with kids

with hearing aids. And then once I joined the implant team, I was actually the coordinator of the team for about nine years before I stepped back to spend more time at home with my kiddos. And now I'm still just seeing cochlear implant patients and working part time for the past, I think about seven years now. So yeah, it's been a journey.

Katie Farnsworth [00:22:34] 20 years. That's incredible.

Beth Tournis [00:22:36] Yeah, it's a long time.

Katie Farnsworth [00:22:35] Happy anniversary. I mean, this is such a huge milestone.

Beth Tournis [00:22:40] Thanks.

Katie Farnsworth [00:22:40] Yeah, it's so exciting.

Beth Tournis [00:22:41] Yeah, it was November of 2000. I always wanted to work with cochlear implants, so there was a position that came open on the team after I had been at Lurie for about two years. And yeah, was November of 2003 when I started. So yeah, crazy.

Katie Colella [00:22:53] It must be crazy to think about the first implant you held to what you're holding today.

Beth Tournis [00:22:59] Oh my gosh, Yes. So when I first started kids, we didn't have their behind the ear processors, which were just, you know, the little ones behind the ear with nothing attached to the body, were just coming out. And they were mainly only being used on adults. And there were only specific brands of cochlear implants that had them. So we worked primarily with two brands at the time, and one of the brands didn't even have a behind the ear processor. So when I started fitting children, actually we would spend sometimes the first 20 minutes of an initial activation just strapping on a little harness so that we could put the box that was the speech processor in the harness. So literally 20 minutes, the appointment was like getting the kid comfortable and fitting the like suspender things to hold their harness in place so that you could put the box that was the device inside. And it was actually bigger than an iPhone, like the size of the the things that they would wear on their body. And then when we started doing bilateral implants, they would have two of those boxes and that was a little bit further along in my career. But yeah, it's crazy just to think the implants that I was doing at the time were analog, so they didn't sound good at all. You could connect to nothing. And now we're connecting to Bluetooth and apps and it has definitely been the technology, when you think about it, it's pretty mind blowing and just how well the kids do. When I first started, I used my sign language a lot more than I do day-to-day today, because now even if I have kiddos who use sign language in addition to spoken language, most of the time they're still understanding my spoken language and I'm not finding out that I have to sign as much during my appointments. So but when I first started that joined the implant team, I went and signed up. I took sign in college and but I wasn't fluent. So I actually took classes at Columbia University in Chicago to up my science skills because I really needed them when I first started on the implant team.

Katie Colella [00:24:46] Wow.

Beth Tournis [00:24:47] Yeah.

Katie Colella [00:24:48] So one thing I've loved talking to Maria about is how she frames the cochlear implant process because she gives us such an emotional, it's through an emotional lens, of how she's feeling through every part. But would you be able to simplify as much as possible what the process is like for a family whose child is getting a cochlear implant?

Beth Tournis [00:25:12] Sure, I will do my best. It's not as simple process as you know, but basically we meet the family as an audiologist. We're kind of their case manager, so we meet them when they come in to our center, where a lot of times the first point of contact for them, if they come from an outside facility like that, that Venalongo family did, they were actually not diagnosed at Lurie. Or Eduardo wasn't diagnosed at Lurie. I can't remember where he was diagnosed. It was a different hospital in the area. And so they came in for a cochlear implant consultation. And so I was the first person they met on the cochlear implant team. There's a series of appointments with audiology. For most young children, it's about 4 to 5 appointments to get all of the testing that we need. And then they meet a myriad of other professionals along the way. So not just the cochlear implant surgeon, but typically an aural habilitation therapist on our team. At that time, we had a psychologist on our team that some of our children saw and then the nurse to get the vaccinations that are necessary for the surgery. So the social workers they always meet with. So there's a lot of different people that they're meeting as they go along. But the audiologist is typically their point of contact, which is awesome. I think it's really nice to form those relationships with families. But when you first meet them and you're giving them all this information about all these appointments that they're going to have to attend and take off work. And then, you know, some families are surprised that there's therapy afterwards and all the programming visits afterwards. So in the first year a child gets a cochlear implant, there's typically about nine appointments with audiology. So that's a lot. Once they've worked through that audiology process beforehand and we've done all the testing to determine that they're a candidate and the surgeon has cleared them from a surgical perspective and they've had their MRI as they're imaging... At the time we we are also doing CT scans at the time Eduardo got implanted. Then they have the surgery and then they come back about 3 to 4 weeks later to see audiology, to have the device activated or turned on. So those are those videos you see on Facebook of the happy baby most of the time, or the ones that make it on Facebook are the ones where the mom says their name and the kid lights up and smiles. And I always tell families that happens one third of the time and the other two thirds of the time that is not the reaction that you get. That was actually the nice thing when I started practicing in the early 2000s, is you didn't have that pressure. Nobody saw those videos on Facebook and no YouTube at the time. It was great. But now we're there, which is fine, and it does help when you are trying to explain to someone what the processes are like. "Oh, I know what that is." So that's the initial activation appointment. And then they we see their kids typically three and six weeks after that to do some testing and then several times throughout the first year to do testing and adjustments. And then of course simultaneously they're going to weekly therapy to learn how to listen with a device. And then as audiologists, we're keeping in close contact with the therapists to make adjustments. That's yeah, a lot of work.

Katie Colella [00:27:57] Simple as that can probably get. Thank you. I think a lot of people don't understand that, what a process it is. You don't just show up and decide you're going to get this for yourself. It's a, it's a thoughtful process because it's a surgical process.

Beth Tournis [00:28:12] Right. I agree. Every family we meet, we're either recommending that they have surgery or not. So it's not a it's not something we take lightly, for sure.

Katie Farnsworth [00:28:19] I also think as a cochlear implant audiologist, yes, we are that first point of contact. But also I think a lot of the really difficult conversations have happened before we even met them, right? Where a diagnostic audiologist has met this family and has confirmed a significant hearing loss. You know, and so I think oftentimes I have families that come in that still have a whole slew of questions, you know, about what the next steps are going to entail. And so I wonder if you have any suggestions for those audiologists who are new to the field or just, you know, have been practicing and maybe continue to struggle with how to counsel these families with more significant diagnosis about like what those next steps are?

Beth Tournis [00:28:59] Yeah, I think it's hard because you don't know how much that family is able to hear in that moment, right? And I think this isn't what drew me to cochlear implants, but one of the awesome things about only seeing cochlear implant patients is I most the time get to have the happy conversations, right? 95% of my visits are your kids doing great or this is what we're going to do to help this. Like, no, they're not hearing well now, but this is what I can provide you with options versus, you know, when I was when I was a diagnostic audiologist and doing ABRs, most of my conversations were not that way. They were your child has a significant hearing loss. And I think, you know, I do think it's hard. You want to offer families hope, but you also want them to understand that the significance of the diagnosis. I think, is there's diagnostic audiologists that haven't had experience working with somebody on a cochlear implant team or a cochlear implant audiologist. I think it's helpful to reach out to your colleagues just to see if there's information. When we have new audiologist in our clinic a lot of times I'll do like a consult with them or I would when I was in the coordinator role if they had a family with a significant hearing loss coming in. And I think it was helpful for them to hear just a really basic rundown of the this is the device, this is what it entails. It's going to be a lot of work. When you go see that person, make sure you bring a list of questions. These are the sites that have reputable information on the Internet. These are the ones to avoid that kind of stuff. So but yeah, I think it is hard.

Katie Colella [00:30:16] And I appreciate that as someone on the diagnostic team where it's sometimes so hard to convince a family to take that next step to get to the evaluation. Even though they'll keep coming back to Lurie. But I always I'm trying to say, just do the evaluation. You're not committing to anything. You're you're just learning to get the evaluation. And the biggest hang up is the concern about surgery.

Beth Tournis [00:30:43] Yeah.

Katie Colella [00:30:43] Is that it involves the surgery versus their the hearing aids that do not.

Beth Tournis [00:30:48] I think so too. And I think, you know, I will say to families because they I think sometimes even when they come in for that first appointment, they're super hesitant. Right. They're like, you could tell they're stressed and they're nervous and they're not sure like, you know what to say. And I always say, you're not signing up for surgery today. In fact, you can do this entire evaluation process. You can meet everyone on our team and we can all tell you your child's a candidate and you can decide then I don't want this and that's fine. But at least you've gotten all the information and you know you can't, um. A lot of times people say, I want my child to be old enough to be able to make that decision for themselves. But by that point, you've already made a decision for them. You made a decision that they're not going to be able likely to learn spoken language. And that's okay, but that you are making a decision by not making a decision. And I think that's

what I always try to, you know, tell families. And it doesn't happen as much these days. But I think when I first started, people didn't know as much about cochlear implants. And I used to get asked all the time, like, if my child gets this, can you guarantee that they're going to talk? And I always used to say, "No, I cannot guarantee that. We'll talk. But I can guarantee you, if your child doesn't get this, they won't talk." And so I think that that was helpful to you just to really be candid and honest with a family like, "No, we don't know what the future holds for your child, but this is just an option. You know, maybe opens up some additional possibilities then if you choose not to pursue this treatment." That's why I always try to phrase it.

Katie Farnsworth [00:32:12] I love that.

Katie Colella [00:32:13] Yeah. Me too.

Katie Farnsworth [00:32:14] I think it's really honest, you know but direct advice to families.

Beth Tournis [00:32:19] And I'm sure I said that to Maria. Just thinking back. Eduardo was earlier on in my career. So I feel like you remember more of those candid conversations and not that I don't remember all my kiddos now, but, you know, once you've done it for 20 years, you may not remember specifics of every appointment, but back then, yeah, he was one of my first. And I definitely remember some of those conversations with her.

Katie Colella [00:32:41] And she's been very open about how well you explained all the information, how much she relied on you, because it is so much information. And I think it's, you know, we're in these short appointment times that so much information to give, we worry about patient retention. Do you have any advice for how we can ensure our patients are retaining the information we need them to?

Beth Tournis [00:33:07] I mean, I feel like if I did, I could really make some money.

Katie Colella [00:33:10] Yeah.

Beth Tournis [00:33:13] No, I think just the typical ways I've worked really hard over the last I don't even know ten years to not say, "Do you have any questions but to say, What questions do you have?" It's a mind change, but it does, I think, empower the family to be like, I should have a question. Or if they do have a question, then not be afraid to ask it. Whereas like I've been at doctors where like, "Do you have any questions? Nope. Good. Okay, see you later." And you're like, "Oh, I did have some questions, but I guess they don't want to hear them." So I try to just ask what questions you have and pause for a beat. I'm not always great about having families explain things back to me, especially because there's so many like technical terms They don't want to like put them on the spot. But I do try to use a lot of visuals. There's a really great picture that has, you know, the cochlea with the cochlear implant inside of it. And it's fun because sometimes, like a family will bring somebody else to a visit. They'll be like, "Can you pull out that picture you showed me when, you know, before they got an implant?" So I do think that that gets through to families. The more visuals we can provide them for sure.

Katie Farnsworth [00:34:14] So tell me a little bit about what you remember, because you've been with the Venalanzo family now for quite some time.

Beth Tournis [00:34:20] Since the beginning. So I met Eduardo when he was three, I believe he was a little bit. It's so sad to talk about that three years old, but in the world of cochlear implants, three is old to get a cochlear implant, even at that time when we typically weren't implanting kids much under 12 months. And so but he came to us from another facility. I remember meeting her and I remember both her, surgeon, Dr. Young and I were struck by the fact that she, part of the reason she came to our center was because the center she was at didn't provide listening therapy after cochlear implantation, and she didn't know very much about cochlear implantation. But she knew that, like the most important part of a surgery is typically the rehab. And so she was like, "This doesn't make sense that they're going to give my kid this device and there's no rehab." So that was she sought out coming to Children's for that. So kudos to her. What an amazing thing. And so I remember that for sure. Eduardo was a pleasure to work with. He was so much fun. And just testing him and getting him hearing. And then I remember her telling me she was pregnant and then Baby Esteban was born and two boys and they were both deaf. And so do you remember some grief over that. But also she was like, It's cool. I know what to do. Like, I'm going to get him an implant. And then I can't remember how it happened in terms of like than it did Eduardo did get a second side and then ,Esteban I don't know if she talked about this, but Esteban they saw something on his MRI. Did she talk about that and that he couldn't wear a magnet for like the first year?

Katie Colella [00:35:51] She did. She she explained a little bit how they shaved the head and put sticker stickers on. But, I mean, you know, she said, okay, So, I mean, really, she just rolled with it.

Beth Tournis [00:36:03] She did. Which was amazing. I only had I have only had that experience with one other patient whose magnet had to be removed so she could have serial MRIs because she had she was ill and needed serial MRI to image, her brain, but that kiddo had already had a cochlear implant. So I think it was a little easier to start from scratch with a kid. And it's hard enough to get a kid who has a magnet to keep it on their head in the beginning and then to be able to do it with a sticker. So it's like it's literally like a sticker that you stick to the skin and it's metal so that when you put the magnet on, it sticks to something like, that's how it works. It's a very low tech system and then you have to kind of make sure that you're in the right spot, which also isn't the easiest thing to do with the sticker because it would move and he would sweat or you would swap out it and swipe at it and then it would just fell off. And so, yeah, it was a challenge in the beginning. And then once they finally cleared him to get the magnet put in was when he got his second side. So he also had a delay in between sides. But both boys do well at wearing both devices, which isn't something you always see when you have a delay between implants. And so that's a testimony to the to that family, too, and how much importance they placed on it. And hard they worked on all of those implants.

Katie Colella [00:37:16] And I believe then Eduardo got his second surgery the same year Esteban got his revision and second implant.

Beth Tournis [00:37:25] I think you are correct.

Katie Colella [00:37:25] Three ears in one year.

Beth Tournis [00:37:27] Then one year. Yeah, I think you are correct on that.

Katie Colella [00:37:28] That's crazy.

Beth Tournis [00:37:29] Right?

Katie Farnsworth [00:37:30] I know the busy year.

Katie Colella [00:37:32] That was way busy..

Beth Tournis [00:37:34] It's a lot. So. Yeah, no, but. But they did great. And when? Yeah, when he had to have, I think we all just thought that he was just going to get a magnet put in. But actually they weren't able to just put the magnet back into Esteban's device, so they had to take it out and put a new one in, which means it doesn't sound exactly the same because if you're even a millimeter off, like it never sounds like when you do a revision, because it's not exactly in the same place in the cochlear, right? So it takes a little bit of like time and training for your brain to adjust again. So yeah, poor kid. I can't remember how old he was. He was little and he was talking and hearing and he went in for the surgery and he woke up and he was hearing completely differently and he couldn't hear for, you know, we had to wait, I think probably two weeks before we even activated it. So that's got to be hard to you as a parent, just, you know, trying to explain to your child. I mean, how do you explain to a toddler that, you know, you're going to have the surgery and you're not going to hear even though you can hear today? So but man, they they went with it and talk about flexible and well adjusted. So that's good. Yeah.

Katie Colella [00:38:33] How long, how has that gap shortened from the beginning of your career? Because I remember it being much longer when I was in grad school of I think I was, I learned 4 to 6 weeks.

Beth Tournis [00:38:47] Yeah. I feel.

Katie Colella [00:38:48] Initially after a surgery to activation.

Beth Tournis [00:38:49] We've always been three to two since I've been on the team. We've always been 3 to 4 weeks, but I think we were on the shorter side. I also think there's a difference between kids and adults. Adults need more healing time and or at least that was the theory back in the day. And so they would they would do it a little bit later. They would wait like the six weeks I've done them as soon as seven days after a revision, it gets a little tricky. Um, just because you really have to make sure things are well-healed because the the device on the inside can move if you do it too soon and you're, you know, kind of moving, inadvertently moving it before things have really like kind of scarred up and healed on the inside of the head. But yeah, it's definitely the time has shortened the even more than that, just the actual procedure itself. So it's it's going to get lost a little bit in a podcast. But when I first started, they were making "S" shaped incisions, so they would go into the hairline. So instead of just going right now we do like a small "C" just behind the ear. I do nothing, let's be very clear, I don't do surgery, but the surgeon does a small "C" just behind the ear and then retracts the skin and puts the implant in. But when I first started, they did an "S" shaped incision so it would go behind the ear and then kind of zigzag back up into the hairline. And so I still see kids actually saw one last week that come in today, they're like boys with short hair. And you can still see the incision line kind of going up on the side of their head where that where that scar is. And actually before I joined the team, when the program first started at Children's that they would do a big "C" like that was like half the head. So I just had my headphones, like half the head and like shave half the head and then do like a big "C" and like flap the whole thing. So it's definitely that the incision has gotten so much smaller, the internal devices have gotten smaller and have changed from a ceramic devices which broke away more frequently to

titanium and silastic like plastic devices. So I've seen like huge changes in that. So which has been great. It's nice that they only shave a teeny tiny bit of hair on some of the kids now rather than when I first started. I'd be like, there's going to they're going to shave like a decent patch. You know, which is probably fine for your you know 18 month old but when you have like an eight year old girl that has to go to school like that was a big deal for some of our patients for sure.

Katie Colella [00:41:11] Yeah. Yeah.

Katie Colella [00:41:13] Wow. Well, what questions do you have for us? Now that we have to Katie's co-hosting this season, we decided to try a segment called Two for Two. Two Katie's, two questions that we have not prepped each other for ahead of time. To follow up on our discussion with Maria, who's amazing, right?

Katie Farnsworth [00:41:47] Oh, my gosh. She was just wonderful and such a cool perspective. And even after a couple of decades, like, I feel like when you were listening to her, it seemed like it was just last week.

Katie Colella [00:41:57] Right. Yes. I felt being in that room with her. Like I was there. Because of just how passionate she describes it. And it was a hard journey for her. So it was touching when she talked about Eduardo being activated for his implant. So my first question for you, Katie Farnsworth, is what was it like when your cochlear implant was activated? You were an adult, so a little different. But I love to hear what it sounded or felt like.

Katie Farnsworth [00:42:34] Yeah, I think I really related to Maria in the sense that I will never forget Activation Day. I mean, Eduardo was implanted, what, almost 20 years ago? And Maria still remembers the date that he was activated. Right? Like, I will never forget where I was, where I was sitting, where Chris was sitting, where my parents were sitting, where his parents were sitting. And that initial turn on. I was admittedly extremely nervous about being activated because I didn't know what to expect. I didn't know if I was going to be able to understand voices or if I was not going to really hear anything at all, if everything was going to be just really um indescribable. For lack of a better word. And when my first when my my implant first turned on, I just remember everything sounded like keys on a piano. Like the world went quiet. And then I heard keys on a piano and I had my eyes closed, actually, when it first turned on. And when I heard those notes, I remember opening my eyes and my dad was talking. And its like all of a sudden it like dawned on me like, "Oh, wow, that was his voice" And then at the same time it was, "Oh, wow, I have no idea what he just said." So it was it was a pretty cool experience, you know, to be able to recognize that I was understanding voices, but I just didn't know what that meant yet. And so it took, you know, quite a bit of time for my brain to be able to put it together and do some short term therapy, even if it was just at home on my time to really put it together.

Katie Colella [00:44:32] Wow.

Katie Farnsworth [00:44:33] Yeah. So. And I'll never forget that. Just like Maria will never forget when Eduardo turned around when he called her, when she called his name. You know, it's such a special moment. And but it can also be a very overwhelming moment if you have a kid who is really upset during the process, because I've also experienced a lot and that, you know, and I mean, I've also had several patients have that experience, too. And I think either way is completely normal. And so that's one thing I keep trying to tell parents, too, that whatever happens in this appointment is normal.

Katie Colella [00:45:16] Mm hmm.

Katie Farnsworth [00:45:17] And that we can build off of. We can build off of that.

Katie Colella [00:45:21] Right. There's no wrong way for a child to react.

Katie Farnsworth [00:45:24] Yeah.

Katie Colella [00:45:26] Just an honest reaction.

Katie Farnsworth [00:45:27] Yeah, exactly. So, Katie Colella, I have a question for you. So Maria talks quite a bit about her initial reaction to finding out that Eduardo had a hearing loss. Also, I mean, a similar reaction that she had where Esteban finding out that he had a hearing loss as well. I'm curious, you know, as a pediatric audiologist and sharing the news to families about their child's diagnosis, what do you think would be your initial reaction if you found out that one of your children had a hearing loss?

Katie Colella [00:46:01] In the scenario that I am a pediatric audiologist, I would have felt heavy I don't you know, I would have felt definitely a calmness because I know what to do. And I know I have so many people, so many colleagues who would support me on the way this journey. But when I have thought about that scenario, which I did both times, when right before both my sons went through there, underwent their first their newborn hearing screening of, I feel that I would carry this pressure with me, that they would have to be the models of pediatric audiology success. Even though that's not true, that's not a fair standard for anyone to put themselves under. In a, in a scenario where I'm not a pediatric audiologist, I think I would take the news rather hard. And I say that because when my during my 20 week ultrasound with my younger son, I learned that he only has one kidney and I was a mess. I was a sloppy crying mess because I had I didn't know anything about kidneys, I don't know much about kidneys. And I was devastated. And now looking back, you know, now today he's fine. We know a lot about it. He's thriving. We have our follow ups as needed. But I think the unknown is just so terrifying. And so I can completely understand when families do react so profoundly to these diagnoses. I think a lot of it is you just don't know what's going on or what this means, and all these terms are new. So I think that's how I would have been if this had ever happened to me. And I wasn't an audiologist. Easily. Yeah, yeah. And I'm a crier.

Katie Farnsworth [00:48:04] So I am too.

Katie Colella [00:48:07] And I'm a sympathetic crier. So don't start crying because I'm going to start crying, you know.

Katie Farnsworth [00:48:12] Two of us are going to start crying.

Katie Farnsworth [00:48:13] Yeah. Well, next episode we're going to talk a lot more about Esteban and we're going to get to chat with Dr. Nancy Young. So until then, thanks for listening.

Katie Farnsworth [00:48:28] *Amplified*, presented by Lurie Children's, is co-hosted by Katie Colella and myself, Katie Farnsworth. Written and edited by Katie Colella. Tech and Website Support by Katie Fanella Artwork by Katrina Garagiola. Special thanks to the Venalonzo family for sharing their story along with Beth Tournis, Dr. Nancy Young, Tatum

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