Adult Perceptions of Hearing Status and Options: Professionals Facilitating a Life-long Hearing Journey, in partnership with American Cochlear Implant Alliance

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- [Announcer] Welcome to the classroom, it's my pleasure to introduce to you Donna Sorkin, she is the Executive Director for the American Cochlear Implant Alliance. She has put together such a wonderful series this year, there is an ACIA series in partnership with AudiologyOnline annually, and this year Donna has put together just a great course with several speakers on adults and children as they move from hearing aids to cochlear implants. I'll hand the mic over to you, Donna.

- I did wanna just say that we are so pleased to, again, collaborate with AudiologyOnline on this series on Adult Assessments in Hearing Healthcare. And this is the fourth in a series on a topic that actually is unpublished as yet, we did do some research on it and we'll be publishing, so you're getting a first look at this topic of what adults think about their hearing status and what their options are, and how US professionals can help them along that journey. There are some other great courses that we've given and one more that will be coming on after, and of course, they'll all be recorded, so you can take them whenever you want in any order that you wish.

So you may wonder who we are as an organization and why there's another organization in hearing health, and we are a membership organization that's focused on cochlear implantation and particularly access to cochlear implants. And our members are from across the care continuum, so we have audiologists and physicians, speech pathologists, educators and others on CI teams, as well as consumers and parents who join to help us with advocacy. And we also have an increasing number of hearing aid specialists who wanna learn more about CI. We're proud of our website that's designed for those who are in and outside of cochlear implants, and we are highly collaborative with other organizations in the field, including AudiologyOnline. So we welcome your involvement and I've given you some places where you can follow us, including our website and Facebook and Twitter, so please do join us.

So our mission is to advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness. And we do try to address those factors that contribute to the under utilization of CI. At present in the United States, we are very underutilized, for children, we're about 50 to 55% of children who could benefit, and for adults it's even less than that, it's between 5 and 10% depending on what candidacy criteria you use. So we really wanna create awareness about candidacy and outcomes and affect people's perceptions as we're going to talk about today. These are my disclosures. And just to review what we're going to learn about today, we're gonna discuss the common concerns about loss of residual hearing and typical speech perception gains, music, quality of life, and options for adults who receive CI, we'll discuss health insurance, and also discuss the surgery, which is a fear for some, and something that holds people back from moving forward.

So we are interested in knowing who's here today, so we're gonna do this poll, if all of you would just indicate who you are, it will help us in terms of knowing how to address this topic. So please go ahead now and just take the poll. Christy, how'd we do? Let's see how we came out. Wow, this is really great, we've really hit our target audience of audiologists who work with hearing aid patients, so thanks to those who have worked outside of their box and joined us today, as well as audiologists who work with both CI and hearing aids and those who are primarily in the CI realm. And wow, we've got 10% for who are hearing aid specialists, so thank you so much for joining us, we really wanna help you move along that continuum as well.

So that's really great, it makes me happy to see all of the people from across the care continuum who are with us today. So this is our agenda. We're gonna talk about the care continuum, we're gonna talk about particularly, perceptions and misconceptions, and the big one, fear, and research relevant to common CI fears, and what candidates and recipients say about what would've helped to get through the journey. And that's something I think we often don't think about. So all of you on with us today, what do

you think accounts for the low utilization of cochlear implants? You see there, we talk about awareness and understanding of candidacy, the perception that insurance doesn't cover, the fact that patients feel they're doing okay with their hearing aids, that there may be better options that don't involve surgery, and concerns about the surgery themselves.

So let's go ahead and put that poll up and please take that poll for us so we can see what you think about this. Okay, let's see what people said. Lack of awareness, absolutely, that's a big one. And I see a lot of you also said concerns about the surgery, that's another big one for people. As is doing okay with hearing aids. And honestly, all of these come up at some level, so that's why we listed them, so thank you so much, we're gonna talk more about all of these as we go along. So fear, fear about so many things is what often keeps people back. And amongst those factors that you just voted on, fear was certainly part of those.

And these are the top concerns that adults had about moving forward with the CI, and this is based on a survey that we did on SurveyMonkey that we conducted in February and March, so very new data that we've just collected. And I'm also gonna share with you the concerns that hearing care professionals think that people have. So we'll get two sets of data, what adult candidates say, or adults who received a cochlear implant, and then we'll also be sharing the data with you about what professionals thought were the key issues. So the top concerns that adults noted were concerns about the surgery, you all indicated that when you took the survey. One that we didn't list there, but is really a big one, and that is people are fearful about losing their residual hearing.

People indicate often they're doing okay with their hearing aids and they're often supplementing their hearing aids with other ways of getting through, and that's a very common one, it's one I hear when I talk to people sometimes that I think would benefit. People are fearful that they would not be able to enjoy music. And we'll talk a bit about

that and just what we find how that has changed over time. The thought that people wanna wait for the technology to improve, that comes up quite a lot, particularly among those who know they're a candidate and decide they wanna wait a little longer. And the perception that CI wasn't covered by health insurance is very, very common, so we'll talk some more about that one as well.

And then this is a listing of the top reasons that were noted by people who were candidates and who chose not to move forward. And big one, they don't wanna lose their residual hearing. So that's what comes up amongst this slightly different population, it's people who know they're a candidate, but they don't wanna get a cochlear implant at this time. I hear a lot of people saying, "Well, I'm waiting for their technology to improve." So we'll talk a little bit about that and whether that's a legitimate concern, actually whether why it's a concern, I shouldn't say legitimate, any concern is a legitimate concern, it's just how we talk about it in terms of what it means to an individual.

Getting along okay with hearing aids, very common. And lastly, concerns about the surgery is also quite a common concern, amongst any surgery, anyone that's getting any surgery is often concerned about the surgery. And some less frequently mentioned from that population of people who are candidates but haven't moved forward is the concern that they wouldn't enjoy music, they wanna wait for the technology to improve. And this last one comes up more amongst those who don't wanna go forward, who haven't gone forward, they're concerned about the way the technology looks on the head, the cosmetic aspect of it. And I think that's one that people sometimes don't wanna talk about, but it's real. And honestly, I experienced that in my own family.

My stepfather was a candidate for a cochlear implant, probably the last five years of his life, and it would've so improved his quality of life had he gotten one. So the person

who discouraged him was my mother, my mother didn't like the way they looked, he was fairly bald, and when I would bring it up, she would say, "Nope, you can't discuss it with him, I don't like the way it looks." So that is a real concern amongst some and something amongst the topics that I'm gonna talk about today, it's the one you really can't do anything about, if someone doesn't like the way it looks, we can't make that part go away. So a little bit different, according to CI clinicians, this was a totally different survey than I did with individuals who actually work with candidates and with people who get a cochlear implant.

And one came up in that group that wasn't mentioned by the candidates, and that was that an individual had other medical issues that took precedence. So they were waiting until they took care of their back surgery or something that was going on. And so that was one, people had concerns about the surgery that overlapped, didn't wanna lose residual hearing, that of course overlapped. And the last two I'd mentioned as being concerns amongst the candidate population who chose not to move forward. So let's talk about all these concerns in terms of what the research says and how that aligns with the reality of those key topics. And the first one, our concerns about the surgery, I hear that less today than I did years ago, there was sometimes some people going around saying that this was brain surgery and it's dangerous, et cetera, et cetera, and of course, it's not anywhere near your brain.

It's typically performed as an outpatient procedure, about one to two hours, it's safe, it's effective. The overall rate of major complications is similar or better than other surgeries at about two to 3%, and there was a recent article in Larynoscope on this. And then some other complications that occur very occasionally are migration of the receiver or the electrode array that may require a second surgery, it's absolutely fixable and can be done, it doesn't affect long-term outcomes. And less common but possible, and it's something that candidates are told about when they go in as part of their evaluation is that there's a possibility for facial paralysis and infection, much less

common, and honestly occurs a lot less now, because we know so much more about the surgery and the device, the eternal device itself has changed over the years.

Some short-term temporary effects may include dizziness and balance issues, tinnitus or an increase in tinnitus if someone already has tinnitus, and sometimes taste disturbances, people often complain about a salty taste. These effects do go away within a week or two weeks, sometimes a little bit longer, but those are common short-term effects. And we have information on our website on the surgery as well as a short video that was done by one of our board members. And we also have a really wonderful Tuesday talk, it's the short talks that we run on the surgery that you can check out, it's designed for the patient population, but it's also great for everybody, so that's also on our website.

Okay, the big one, loss of residual hearing. And some of this is a result of the fact that early on in this intervention, CI surgery meant that patients lost all of their residual hearing. And I'm gonna insert some personal experience here, I've had a cochlear implant for 30 years, I was an early adopter and that was definitely what I was told in 1992, that I would lose residual hearing in the implanted ear. And that in fact was the case, I have no residual hearing in my implanted ear. I have residual hearing in my contralateral ear, my other ear for sure, but it's gone in the ear that was implanted. I didn't care, I had so little hearing, I was getting so little benefit from hearing aids that, that factor just didn't matter to me.

But this factor is no longer the case. Patients don't lose all of their hearing, some patients retain a good bit of their residual hearing, and that's because we have modified the surgery and we use what's called soft surgery, and there are techniques, like intraoperative adjustments that are used by the surgeon during the insertion of the electrode array, and that helps to preserve the existing hearing. And the devices themselves have changed, and that is now something that is a goal, so we have

thought about it in different ways. And in fact, we have electroacoustic devices that combine cochlear implants and hearing aids in the same ear and provide improved hearing and quality of life. So that means the individual can take advantage of both their natural residual hearing and their electrical hearing from the cochlear implant and get the best of both worlds.

And studies show that many patients have at least some residual hearing, if not most of their residual hearing. And it's almost always the case that people gain much more than they lose, and I'm gonna share some of that information with you about what the increase is. And I've given you some references there on loss of residual hearing, both from Dr. Gantz, a very early CI surgeon, and Oliver Adunka who's actually conducting a clinical study with MIH now. So you can take a look at those. Another common one that we hear from people is that they're getting by with their hearing aids, and that people do get accustomed to the way they're doing things, and they keep adding other ways of getting by, they use assistive devices, and captioning, and lipreading, they have a hearing dog, of course, we now have texting and email that we didn't have in the day when I went through this.

So they're getting by and very often they don't realize how poorly they really are doing with their hearing aid alone. Sometimes people are just flabbergasted when their hearing care professionals shows them that they're only getting 17% without lipreading or something like that. And they just don't know how much better they will do with a cochlear implant, 'cause many of us don't recognize or know what those improvements are, and I'm gonna show you what some of them are. And people can still use a hearing aid on the contralateral ear and that is really encouraged. So for those of you that are in the hearing aid realm outside of CI, you're not gonna lose your patient, they're just gonna love you more, because they are getting so much additional hearing from the cochlear implant.

And we always encourage people to continue to use a hearing aid on the other side. So there's fear of that unknown, and really human nature is, keep doing what you're doing, we all do that in all kinds of ways, and I'm not surprised that people have that fear of the unknown and a hesitancy to move beyond what they're doing right now, because they just are fearful about things being worse than they are at present and it's just something they're familiar with and accustomed to. So I'm gonna share a recent study with you, and this is actually the study that we sponsored to expand the Medicare candidacy recently. So last September, Medicare CMS announced that they were going to expand the Medicare candidacy so that it was more similar to the FDI candidacy for older adults.

And so this was the study that we conducted that was submitted and helped in that change. And it involved 34 Medicare beneficiaries, median age of 73.6. Their deafness had been in effect, I wanna say about 10 years, so these were people who were longtime hearing aid users. Their pre-op baseline sentence scores in best aided condition were 53% bilaterally. So they had some benefit for sure from their hearing aids. In the ear to be implanted alone with the hearing aid on, they were getting 24%, and then 12 months post CI, they jumped from that 53% bilaterally with hearing aids on to 89% bilaterally. And they jumped from 24% in that ear to be implanted to 77% in the CI ear alone. So dramatic change for this group of people, and they were so happy with the benefits that they received.

So that's a median change in best aided and CI alone of 36% bilaterally, and in the implanted ear alone of 53%. So big, big change. And then this study was submitted to CMS and led to the revision in Medicare candidacy. And there's been a lot written about that, you could find out more about it, there was an article in the Hearing Journal in January and then we also published about it in the Winter Issue of Hearing Life, which is the magazine of HLAA, Hearing Loss Association of America, the organization for adults with hearing loss. This is a visual representation of what I just took you

through, and you can just see the change that occurred at six months and 12 months, honestly that change that I shared with you was available to people after six months.

These were AzBio sentence scores in best aided for both ears and then for CI alone, so you can just see visually what I just showed you, and again, this study is discussed in more detail in the two publications I mentioned, the Hearing Journal and Hearing Life. So this is a common one, I thought I would not enjoy music, and the conventional wisdom and what we used to tell people back in the day when I got my cochlear implant was that CI recipients don't enjoy music. And this is because pitch isn't handled well by cochlear implants, which is true, and pitch determines melody, so don't even bother trying, and that's kind of what I was told back in the day.

And I was sad, because I had played classical guitar when I was younger and I love music, but the main thing for me was being able to communicate, and I'm gonna tell you more about my own hearing characteristics later. But music as it turns out, is something that we can enjoy and it's not a competition, although some people would cochlear implants are professional musicians or dancers, and so they are able to use the sound that they get to perceive music. And even more importantly, it allows us to enjoy music, and what we find is that there are some tools and tricks that we can tell people about that will help them to enjoy music, and one is, for example, having the words to songs.

It is hard to pick out the words to a song if it's a new song, if it's one that you didn't know before you lost your hearing. So having those in front of you can help. Alexa can play songs for you and you can read along with the words to a song. The other thing that can help is having music with a strong rhythm, because rhythm, as it turns out, with a cochlear implant is near normal. And so that's a factor that you could think about in terms of the kind of music people listen to, and practice and knowing how to

listen and keeping expectations appropriate, I think is really important. And after all, music is about enjoyment.

I go to musicals with my husband at the Kennedy Center and it's the whole experience of being in a beautiful place and there's a visual component, and I do enjoy the music, I do know that it's not the way I heard music when I had typical hearing, but I do enjoy it. And so I think that's an important component to share with people. The other thing to know is that there are a set of practice tools that people can use. One of my favorites is called Angel Sound, which is free and available on the web. And I pitch trained with Angel Sound, and it was sort of funny after I did that, I did improve my pitch perception, and my husband, who we joke about as being a hearing person who's tone deaf, actually would do less well on those exercises than me.

So that's also important to know. So here's another one that we hear about, waiting for the technology to improve, and someone being unwilling to move forward, because they're waiting for the next generation. In reality, most enhancements occur via the external sound processor, and the internal device is designed to last a lifetime, and so all three CI companies insert their enhancements mostly in those external devices, which change every four to five years, and you can upgrade those without needing another surgery. So I've had my internal device for over 30 years, and in that time, I've had seven processors since that original surgery, with insurance coverage of those upgrades. And the frequency with which you can upgrade through insurance, and co-pays of course, varies by insurance, but in my case, my insurance typically paid for 85% of the cost of the processor upgrade.

And then I've just shown you visually what my first four looked like. The one on the far left was my first body worn processor. And then about a year later I upgraded to that second one, and that was probably the most extraordinary upgrade that I had in my history of upgrades. In that instance, I went from not really being able to use the phone

to being able to use the phone within about three weeks and being able to use the phone so well that people on the other end who didn't know me didn't know that I was deaf. So big change that occurred in that processor upgrade. The next one that you see there was when my device manufacturer moved to an ear-level device, and honestly that one didn't provide the same amount of speech perception ability as my body worn, and I used to go back and forth wearing it, but it was nice to have an ear-level device.

And then that fourth one shown there got me back to having a very robust ability to hear and listen and understand speech, and to be able to do that on an ear-level device. And the other thing that happened with that device that was really quite unexpected, it was at that point that the device gave us a larger grab of sound. And I'm going to digress here and tell you a story, 'cause I think it's a good example of what I'm talking about in terms of the changes that occur over time. Outside of my house, we have a large wooded area and a family of owls that lived there, and my son, who was always so anxious for me to hear everything that was going on would say, "Mommy, did you hear it?

Did you hear the owl?" And up until that fourth processor, I never did. And then that processor gave me the ability to hear more sounds at a distance and then I was able to hear the owl. It's a very distinctive sound as you know, and it was quite far away, high up on a tree, but that processor, that ability to grab a bigger field of sound allowed me to hear sounds that I hadn't been able to hear it at a distance before. And then there were three more that don't have pictures of, but each time we've added to the ability of someone to have an improved hearing experience, I've mentioned the size and configuration, they're now off the ear devices that don't have anything on the ear, it's a button on the head.

I mentioned a larger grab of sound, I personally love Bluetooth for my cell phone, for TV, to connect to the computer. And so we're able to have that same benefit from Bluetooth that typical hearing people hear or hearing aid users hear with Bluetooth, and the improvement in noise programs is definitely something that I have enjoyed. In fact, sometimes when I'm in a noisy environment and I make sure I have my noise program on, which I can even make small adjustments to, I'm sometimes better able to perceive conversations than the circle of my friends who maybe have some decline in hearing are able to hear in that same situation. So this is a really important set of information for you to have in talking to people who are waiting for the technology to improve.

And then health insurance coverage, most hearing needs are not typically covered, there is some policies that do cover hearing aids, and because hearing aids are often not covered, people may assume that cochlear implants are also not covered. In fact, they're covered by about 90% or more private health insurance plans by Medicare, by Medicaid, everywhere for children, and in most states for adults, and we're actually working to expand that coverage for adults in those states that currently don't provide adult coverage. They're covered by the VA, by TRICARE, and by Affordable Care Act marketplace plans. So this is typically a covered intervention, sometimes the way they cover varies for sure, whether they'll cover, for example, for children the single-sided deafness, whether they cover for adults for SSD, so there are that variations, but for traditional bilateral cochlear implants, we see coverage across the board.

And then the other thing that sometimes I hear people talking about is the co-pays, and that will vary by health insurance, by what it is, by the plan. And keep in mind, I think people sometimes forget this, there are co-pays for any health intervention. And sometimes it's not that much money, when I go for PT it's $25 on top of my PT visit, which can add up if you're doing PT for two months. So just, we have to remind people that this is part of our US healthcare system, there are co-pays. So there's information

about insurance on our website and some ways to keep that cost down if the individual is sure that their particular CI manufacturer's considered in-network by their health insurance plan.

So I won't go into details here, but we talk about that on the site and it's a way to keep the cost down for sure. So I'm gonna tell some stories now. That's me in 1992. I had a progressive hearing loss that had been identified when I was in elementary school, it was quite mild at that point and didn't start until after 4,000 hertz. So in the day we didn't do anything about children who had mild higher frequency hearing loss, we do now, but we didn't then. And as I aged it progressed, and I had a very steeply sloping audiogram, and remember this is before digital hearing aids, so it was all analog, and towards the end I wasn't getting any help at all, with my most high-tech hearing aids, which at that time were digitally programmable, but not more than that.

I really couldn't understand, I couldn't see your face, maybe 4% of what you were saying, which is just guessing, so I was relying very heavily on being able to lipread. I had a very high communication job outside of this field at the time and would often be leading groups of 12 or 15 around a table. And it was excruciating, exhausting, frightening, 'cause I never knew whether I would be able to do it or not, and I got to the point at the end where I would request that my client would have a secretary sit beside me and type, so I had some solutions that I was working at. I've always done a lot of public speaking, and when I would give a talk on a stage, when it was time for questions, I would walk off the stage and into the audience.

People thought I was being very interactive, I was just trying to get close enough to be able to see and hear who was asking the question and what they were saying. I was lucky that the ADA was beginning to impact societal perspectives about disability. And so that was starting to happen, but it hadn't really been implemented yet at that time, so I didn't have those benefits. There was no internet, just think about how much all of

us are changed by email and text messaging, so I didn't have that, I didn't have the ability to talk to people in a written mode as we do now. There was starting to be more openness about hearing loss, but social events and more were extremely challenging for me, and in my case, my husband was a vice president at a technology company, and I would need to come with him to go to important social events.

And I would prepare a day or two or three in advance just in memorizing people's names, these people didn't necessarily have name tags on, and some tidbits about each of the people who would be coming and likely I would interact with. So a lot of preparation for social events and work events, because of the fact that I was getting so little sound. And very little awareness about cochlear implants at that time, I really didn't even know what they were, remember no internet, no way to look these things up. Information was accessed through books in the library. And so that's what I did on any number of occasions, and there wasn't anything in any of the books I looked at.

So I was realizing that I really needed to reinvent my life, I thought I would not be able to have jobs and social events that involved lots of other people and in noisy situations with low light. So why did I move forward and what helped me move forward? And the big factor was I had support. I mentioned I was getting very little auditorial aid from my hearing aids, I was so exhausted all the time. And what happened was my wonderful audiologist suggested that I explore cochlear implants. I didn't even know what they were. And she said, "I've done everything I can for you with hearing aids, you've got the most high tech hearing aids on the market right now, but you're still not doing very well."

And she did it in a gentle way, just the right amount of suggestion. Not judgmental, she put me in control by giving me the names of patients of hers who had gotten cochlear implants, and encouraged me to talk to them, which I did. And she supported me in the journey all along the way, and so for that, I actually have never forgotten her, and have

sent her literally dozens of patients, because she did such an important part of my journey in terms of telling me what to do. I also was very lucky to have an internist that knew a little bit about hearing loss, and he explored the CI candidacy and helped me find a center, because you couldn't come on the American Cochlear Implant Alliance website and find the map that has CI centers like you can now, and he called around and he even spoke to the surgeon.

I was fortunate also to have great family support as well as friends who cheered me on every step of the way. So that was a really great part of what I had as well. So it made it possible for me to move forward, and as hearing care professionals, you have a really important role in helping your patients over the hump to know how much they might benefit from this other intervention, and honestly, I think the best thing is not to wait to the point where I was, where I was really helpless, but to tell people about it long before they're a candidate, so it doesn't seem like a last resort, it's something that they know is there if they need it, and will help them do better than they're currently doing.

So what happened? That's me two years after I was activated. That was a picture that appeared in Parade magazine in January of 1995, that was on Hearing Technology, Parade isn't really that well known anymore, but at the time it was was in every newspaper around the country practically, so it was a big deal, and it really helped cochlear implants be better known and out there. And I think in my case, I was very lucky to do as well as I did, the outcomes at that timeframe were more variable than they are today, because at that point people typically had longer periods of deafness and less residual hearing, and those are both factors that we know, if people have a shorter period of deafness and more residual hearing, they tend to do better with the cochlear implant than if they wait.

And I didn't have much hearing, but I hadn't been deaf for that long, so that was something that helped me. And the key impacts for me then and now are on work, my

ability to really travel the world and be an advocate for hearing care and cochlear implants, and be able to function in a range of different settings to have that ability to be part of social and family interactions without being uncomfortable. Do I hear everything all the time? Of course not, but do I think I will be able to participate? Yes, I know I will. And so it's a confidence builder for people who sometimes have shied away from doing those activities that they used to do but feel uncomfortable doing now.

We know that now it has an impact on quality of life and that's been measured and discussed in different ways. One of our sessions in this series was done by Dr. Teddy McRacken and he talks about some of those quality of life changes that occur. In my case, my wonderful internist who supported me, looked back at my health records, and he maintains that I had fewer infections during the winter months than I did after I got my CI, fewer infections after I got my CI than before. And we both wondered if that was because of reduced stress, the fact that I was doing this very difficult high communication job and was so stressed out, so tired all the time, and that that might in fact have affected my health, there hadn't been any studies on that, I'm just telling you what my experience was.

So I did continue to benefit from the technology improvements, I showed you that timeline of how the processors are changed over time, and that was without additional surgery. I'm on my seventh sound processor and have really unlimited opportunity to continue to contribute to this field, which is so important to all of us. And so once someone asked me if I got the cochlear implant because I was involved in hearing health, or was it hearing health that gave it, and honestly, it was getting a cochlear implant that allowed me to contribute, because I got it actually at the same time I became involved in this field, it was really exactly the same time. So one other thing I wanna leave with you, as part of the research we did, we asked adults what would've helped them through the journey, and the number one thing was meeting in person

with someone who had a cochlear implant so that they could ask them questions and see the technology and get a personal perspective.

And that certainly was important to me. And virtual meetups were also considered to be helpful, but they really want in person if they can. And then they mentioned having access to research based information in a format that's accessible to the individual and to their family as being a really important support that would've helped them that they didn't necessarily have. And a pitch here, our website has that kind of information that we have made relevant to the general public, because we do understand that it, of course, was confirmed in this research that we did recently. And people also mentioned having greater availability to clinicians who could answer their questions and concerns. And I think sometimes we move people through the system so quickly that we forget that that part of it is also important to stop and really give them time to explore those concerns that they have.

One person in the survey mentioned kindness, so certainly that's something we do need to think about, because honestly, empathy matters, and I have managed to lose where I was here, let me get back. Okay, ending with some great resources for you and your patients. We do have the website that I've talked about, some of the more popular sections are steps to a cochlear implant and the Q&A section. We have videos on some of those key concerns, like surgery and insurance. We have wonderful stories that we have developed on cochlear implant recipients and family members. And then we've recently started something that we call Tuesday talks, which are once a month on Tuesdays, and they are given by, usually clinicians in the field, but we also have some that are on educational issues, one wonderful one that was done by a father of a young man who has to cochlear implant, and he is an attorney who works on IDA issues and surgery mapping, the device rehabilitation, we had one this week that was on what happens at the cochlear implant evaluation.

And then something we were looking to start up is a virtual meetup with a recipient to help with that topic that I mentioned of being able to interact with a recipient and how that would help someone to move through the process. There are some really nice online communities and I think for adults, my favorite is probably CI Experiences Facebook group. And it's huge, I think they have 45,000 members. I think the moderators for that group, who are all individuals who know a lot about cochlear implants, do a fantastic job of just keeping things on an even keel, keeping it so that it's not judgmental. And largely it's a way for someone to explore questions that they may have or concerns that they have.

So I go on it frequently to answer questions and I really think it's great, so I think it's a place you can safely send your patients to, there's a comparable one for parents with many of the same people involved. So those are two great resources you can look at, and I mentioned earlier the ACI Alliance website. So thank you very much for joining us today, and again, a shout out to AudiologyOnline for working with us on these courses, and we have time for some questions, I think we have about five minutes left, so please go ahead and type in your questions in the chat box and I'd be happy to answer them. It looks like there's some that are there already, let's see what's there.

How many people responded to the SurveyMonkey? So we had about 130 recipients, that might be a little bit more now, I should say recipients and candidates, so those were the candidate and CI recipient population. And then the other survey involving professionals was about 95. So we had a really strong response for both of those, it's still open and so I'll probably close it down soon, and then as I mentioned, we will be writing this up to be published hopefully in a peer review publication. Okay, here's another great question. How should we as clinicians advise patients on the possibility of a device failure? Literature suggests an increasing trend, which is different from what CI manufacturers must report, and clinics can report it as a failure, even if the manufacturer does not.

I think the best way to discuss that is, is during the candidacy process, I think it's fine to give people the best data that you can find, I agree that it's confusing, because it's retained in different ways by the professional community, the scientific community and the manufacturers. There are sometimes failures that are soft failures, which means they happen slowly and they're more difficult to identify. But I think the responses, it doesn't happen that often. I think some of the data that show an increase in failure rates relate to my generation of cochlear implants. So I was implanted in 1992 and as time goes on, some of those are failing. I think in my case, it's maybe seven or 8%, I could be wrong on that, but that's what I recall from reading the literature.

There have been some devices in the past that had issues, they're always taken off the market, and once that's determined, those devices that are having issues are taken off the market. I think the best thing you can do is to be honest and say to people that's what's going on. Okay, here's one from Stacy, thanks for sharing the data, love seeing the positive change over my 35 year career, yes, it's been an amazing change. And then Kevin is asking, does it help to increase the volume of music when listening via CI? No, the opposite is the case, you don't want to jack up the volume, it should be comfortable. I think what helps is to have a clean signal, to listen in a quiet room, one of the best places to listen to music is actually in the car, because you're in a contained space.

I love listening to music in my own house, and I mentioned before, if it's music that has words to a song, putting the captions on for the words to a song, repeat it, listening to the same piece is often helpful. So those are some of my lessons. Okay, Stacy's asking, I think educating or planting the seed with our patients and parents is what really gets them emotionally ready for acceptance, for change and realistic expectations for the journey to come. That is a really great comment, Stacy, thank you for making that comment. I think it's really important that you do it early for just what

you said, planting the seed. But the other reason is, it's comforting to someone to know that as they're hearing changes, there is something that will help them do better, not worse, and I honestly was so depressed during that last year or so before I knew about cochlear implants.

I just didn't know what I was gonna do with my life, and how helpful it would've been to have known that there was this intervention and that people did really well with that, so great comment and thanks for sharing that. Okay, so this is from Kimberly and she says, do you have any resources for persons post implant? I have a friend who's now bilaterally implanted who's been disappointed with the benefit, though those around her notice huge improvements, she does not. I also think if she could look at her own changes over time in terms of her listening outcomes, that that might make her feel better about where she is at this point in time. And it's definitely the case that people improve over time.

I've even improved over time and I've been benefiting from this for 30 years. So I think those are some things that might definitely help her. Okay, good question, from an anonymous attendee, does Medicare cover bilateral CI? It does not. I don't know whether it will in the future, it took us eight years to get the expansion in Medicare criteria, it's certainly something that people want us to try to work on, and potentially we will, so good question, I'm sorry to give you a negative answer on there. And then another individual says, after the first year, are there improved benefits that occur with speech perception with CI users? Absolutely, most of that benefit comes in the first year, but I think that it's very individualized, but I think think people do continue to benefit over time.

Small changes, music may sound better, you learn to use the sound that you have in different ways, so that's certainly a possibility. I wouldn't say no, I would say the biggest changes happen in the first year, but you continue to improve. I did, I continued

to improve over time. So it looks like we have answered all the questions, I wanna thank everybody for joining us today and also putting forth those great questions. And please take a look at the other topics that we did in this series and join us on some of our other opportunities that we have from ACI Alliance. And thank you to AudiologyOnline.