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LISTENING TO MUSIC WITH A CI OR HEARING AID

PRESENTER: KATHY ALLEN

KATHY ALLEN: I am a bilateral cochlear implant recipient. I am very happy to be here today to share with you some of my knowledge about enjoying music with a hearing loss, whether you have a cochlear implant, a hearing aid, or both. What makes me so qualified to talk about music and hearing loss is I have loved music virtually my entire life, even with a severe to profound hearing loss from the age of five.

I was born with a severe to profound hearing loss which was not diagnosed until I went kindergarten. At the time, the teacher said, “Kathy is not paying attention.” My parents said, “Kathy never pays attention so why is that a problem?” The teachers said they thought there might be something wrong. I was taken for a hearing test and we found out that I was not able to hear very well.

The doctors who diagnosed my hearing loss said it was so severe that I would probably not be educable, and that I should be placed in an institution. Thank God, my parents were incredibly stubborn. They could not think of parting with me by placing me in a school for the deaf, even an oral school, which was only twenty miles from our home in St. Louis because I would have to live there. I was their first-born. They found a great program at the Southern Illinois University where they taught me how to lip-read very well and how to make use of one hearing aid. I also had a great deal of speech therapy and auditory training.

I actually did very well in school, getting mostly A’s and B’s. Then, in the fifth grade, I wanted to join the band. I didn't realize that my hearing loss would prevent me from hearing the music. I just wanted to be a part of something. So I joined the band and because my parents were poor, the only instrument that we could get for free was the oboe. I learned to play the oboe, but I couldn't hear it. I didn't care. I was a part of something.

One day, the teacher said, “Kathy, you’re just not hearing well or hearing what you’re supposed to do.” She changed me to the tenor saxophone, thinking that I would be able to

hear that better. Then she said, “You’re not hearing sharps and flats.” I am like, “What are those?” They say that they are putting me on the drums because then I could feel what I was doing. Even on the drums, I could not hear the rest of the band, but I didn't care. I was a part of something.

In high school, I remember the first day of my freshman year when we were supposed to show up two weeks early for marching band practice. I got there but I was so lost because the movements in the marching band had to do with a certain part of the music. I couldn't hear the music, so how was I going to be a part of the marching band? I went home crying that day telling my mom my band career was over.

Mom, being the strong person she is, dragged me back to school and met with the band director. She explained, “Kathy can't hear the rest of the band. She has got a severe hearing loss. How can we work it out so she can be a part of this marching band?” “Well,” the director said, “technically, the drummers lead the band, so we can show her at what parts of the music she would need to make a move and how.” They worked extra hard at teaching me where to make the moves based on the drum cadences, and it worked out very well. I was able to play in the band and I enjoyed it. It was just a really great experience for me.

As we know, living with hearing loss can be very isolating. You are left out of large groups, groups of kids, and from family outings and family gatherings. I didn't understand why. I just knew I was lonely and I needed to be a part of something. So I went ahead and played the drums. I played them through one year of college, even though I could not hear the rest of the band. How I did it I have no idea.

I also developed a love for music because my sister played records all the time, and we spent hours and hours in our bedroom listening to the record player. She spent a lot of time writing down the words to songs for me and singing along so that I could learn to lip sync and sing along with her.
So I love music.

I could hear the beat and maybe some of the really low-pitched tones. I remember especially loving Tony Orlando and Dawn. I couldn't hear what they were saying but my sister was always by my side telling me what they were saying and telling me to sing along with the music. I was always nudging her, “What did they say?” She was always glad to help me out, always there for me all my life. And I really developed a love and appreciation for music.

However, as I become older, I got two hearing aids. These hearing aids were so painful for me. I had the most powerful ones my entire life. My ears were red every day from

wearing these hearing aids even though I couldn't really hear what was being said or much of anything except some environmental sounds.

I am beginning to withdraw and become depressed and more and more isolated which my dad noticed. He said, "Why don't you get a cochlear implant?"

My answer was, "Heck, no! Are you nuts? I am not even a candidate for one. I was born deaf. I can't get it. I wouldn't even do well." Not to mention, I was a member of the Deaf community at this time, and all my friends said, "You will have a hole in your head. You can't go swimming and you will have to give up sports." So no way was I doing that.

However, my dad, who had always searched for the cure for my hearing loss, persisted. I wanted him to stop and just accept the fact that I could not hear. I am the type of person who never makes a bet that I know I am going to lose. With that belief, I decided that I would make my dad a bet that I could win. I told him, "I will get an evaluation for the cochlear implant and prove to you that I am not a candidate. And then you will drop the subject forever and you will learn some sign language." We shook on it. I was so sure I was going to win this bet.

I got my cochlear implant evaluation, and they said, "You are really not a good candidate." I am like, yes! "But ... if you do some therapy, and some listening practice, you could get a little more than environmental sounds."

Then came the kicker. They had me meet with someone who had a cochlear implant, a big music lover, who had a similar background as I did. When we went to meet with her, my dad and mom and I took her out to, of all places, a dark and noisy restaurant. I couldn't hear a darn thing they were saying, and she was keeping up with everything. What I did hear was that she loved music with her implant. She is a huge Beatles fan and I am like, "Wow."

Music perked me up. I was at the point I would have to take my hearing aids off and that meant no longer hearing music, or at least the little bit that I could hear. It was just so dark and dreary and silent not being able to hear anything at all.

So I said, "Dad, I think you have won this bet. I will go ahead and have the cochlear implant done." The audiologist warned me that I might only get environmental sound. I said, "That's fine. All I want is music."

The audiologist also said that if I did some therapy, I would be able to get a lot more. So, of course, I did the therapy. I practiced and practiced and practiced listening to music until it become familiar to me again.

That is to be the theme of the presentation today.

When you have hearing loss and you get a cochlear implant, music is not going to sound the same. If you just have hearing aids and your loss is progressive, music is not going to sound the same. We are all going to experience this loss. But the hope and the fact is if you are willing to invest the time and practice and follow some of the tips that I am going to share with you, music can be enjoyable.

Will it ever be perfect? No. But it can be good enough for you to enjoy it and like it. The more and more you practice with music, the better music will sound. That I know because I have lived it. This is one of my favorite quotes from George Eliot: “I think I should have no other mortal wants if I could always have plenty of music. It seems to infuse strength into my limbs and ideas into my brain. Life seems to go on without effort when I am filled with music.”

Before a presentation, I always get really nervous. I shake. It is just so hard to get up here and present in front of a lot of people. So I put on my I-pod, turn on the music and play one of my favorite songs. That helps calm me down. Music gives me encouragement to do well, and it clears my mind. Music is one of the best things to help me get focused for a presentation.

Also, when I'm feeling stressed, listening to music helps clear my mind so that I can think up some good ideas and get refocused. Music is a critical component of my life. I am sure it is in yours or you wouldn't be here today.

So where do we start with music?

First of all, we need to know why music is so challenging when we have a hearing loss. Then, what can we do to develop those listening skills to make music not so challenging? I will also discuss a few accessories that we can use to improve the sound quality when listening to music. I will talk about creating a play list of songs that are familiar to you, or if you are not familiar with music, songs that could be easier for you to hear and begin to enjoy music. Basically throughout this presentation, the theme is practice makes perfect. “Perfect” is probably too strong of a word. Practice does make it better.

So why is music so challenging? First of all, music is made up of rhythm, and the tone or the timbre. It is played with various musical instruments and the voice. We have to deal with pitch, the high or low notes, all of this together. When you have a singer and music in the background, how are you going to be able to understand the words? Even normal, hearing people have trouble understanding all the words to music. They sometimes get it after listening to it over and over. So why should we be different? Yes, it is more challenging for us. It is going to take longer. But, I can give you some tips to make it easier.

Other factors we need to consider are hearing history. Have you had hearing loss your entire life? Or was it sudden? Or is it progressive? All of those things are really important. Someone who has been hearing most of their life and has a sudden hearing loss is going to have a very good memory of what music sounds like. Listening to music again for those individuals is more challenging than it is for those of us who have had hearing loss our entire life or had a progressive hearing loss.

Sometimes when you have a memory of how good it was, you have the knowledge of all these pitches and everything that goes on, you expect it to sound the same. It won't. Even with the best cochlear implant, it will never be the same because normal hearing has so many different pitches that you can pick up. With cochlear implants, you are still only getting a limited number of pitches.

So we also need to know the length of the severe to profound hearing loss as well as the experience with music. Once a concert pianist come to me and said, "It just doesn't sound the same." That is an example of someone who had normal hearing and then had hearing loss and expectations were so high. She wanted to be that concert pianist again. Doesn't mean she can't. She certainly can. She would have to retrain herself to recognize what she is able to hear now with her cochlear implant or with her hearing aid, and that takes time and practice.

Motivation is really critical. When we really want something, we are more apt to do the work it takes to get it. Right? Once a man said to me, "I really want to enjoy music again, but it sounds so horrible. It is just not working."

I asked, "Are you willing to practice 15 minutes every single day, maybe increasing that to thirty minutes?" He said, "But it sounds horrible. I just can't stand it." I said that it was like that for me, too. I had to practice. I had to listen to it until it began to sound better. He said, "I just don't have the time to do this. I am retired." (Laughter.)

So, again, anything that is important to you is worth the effort. You have to suffer a little bit before you can succeed. The most important thing when it comes to music is attitude. If you keep a positive attitude, you will go far. Keep telling yourself it will get better instead of "I hate this!" You don't help yourself with an attitude like that. Think of having a positive attitude.

How do you face the challenge? First, understand that it will take time and effort. Accept that music may never sound exactly the way you remember. Then start with simple or familiar music. Do you have a favorite song or tune that you used to enjoy? Go back to that tune and listen to it over and over and over again until it starts to sound familiar again.

I remember the first time I went back to listening to Tony Orlando and thought, this doesn't sound like Tony. The music is not doing what I remember. But the audiologist said to keep trying. She was right. After a couple of days of listening to it, Tony started to sound like Tony, and I could get my "knock three times" going with Tony.

So how do you do it?

Set up a listening schedule for yourself. You might want to think of doing this early in the morning when you are feeling fresh. You are going to be more focused and more willing to face the challenge of trying. If you are really tired after a long day, you are going to want something more soothing and music practice may not be soothing. It may be frustrating, and you are more apt to give up.

Keep a journal to track your progress. Write down how horrible the music sounds the first couple of times and write down any small improvements you might notice. Sometimes I notice, oh, I just got that word! I got that phrase.

Find something positive to listen to or start with children's music or holiday songs. We all know holiday songs, and they are probably the easiest to pick up.

Experiment with different accessories. I'm going to talk about personal audio cables, TV hi-fi cables, the HATIS, the Clear Sounds neck loop, and the NoizFree.

Create the best listening environment for yourself. You can do that with CD players or cassette tapes. You can use I-Pods or MP3 players or the television with DVD or VCR and watch the music videos. Find a place that is quiet so that you can relax and enjoy music. Get a direct connection.

Practice with simple or familiar music. Get the printed lyrics, if you can. If you Google the name of the song followed by "lyrics" you will be directed to a site that gives you the words to that song. You can listen to the song or listen with somebody who knows the song. That person can lip sync for you so you can learn where to put the words and how to listen for the words in that song.

Control the sound quality with a graphic equalizer where you can raise up the bass, lower the treble, and adjust things to make the music sound good to you. Be patient. I can't say that enough.

Try some headphones. Some are T-coil compatible. Others, like the Bose noise canceling headphones are good. You get excellent sound quality from them. You can put them right over your hearing aid although the hearing aid does cause some squealing. You can put

them over your cochlear implant and your hearing aid. If you use a T-coil, you are not going to get that squealing with the hearing aid.

AUDIENCE MEMBER: The HATIS is excellent. I use my telecoils. No feedback. But you need to have behind the ear aids.

AUDIENCE MEMBER: If you use a Clear Sound neck loop and plug it into an I-Pod, do you hear the separation of channels?

KATHY ALLEN: No. You will not hear any channel separation. You should be in stereo sound. For hard-wired devices, you use an accessory patch cord that will come with your cochlear implant. Hearing aids don't really come with these patch cords unless there are new models I'm not aware of. With hearing aids, you can use headphones or use good speakers in a quiet room.

The personal audio cable that comes with your cochlear implant will patch directly into your I-Pod. The other end goes into your cochlear implant. This brings the sound directly into your ear and cuts out all of the background noise in the room. However, be aware to use the personal audio cable with only battery-operated components. Don't use it with something plugged into the wall because it does not have a surge protector.

The other thing I use is a HATIS. It looks like a very thin hearing aid. You set it on the back of your ear. You can get a bilateral version if you have a hearing aid and a cochlear implant, or two cochlear implants, or two hearing aids. Put your device on telecoil. Plug the HATIS into your I-Pod or CD player, and you will be able to enjoy music without having background interference.

AUDIENCE MEMBER: Do all the things you are talking about apply also to Advanced Bionics?

KATHY ALLEN: To my knowledge, Advanced Bionics does have a personal audio cable and telecoil. If your device has a telecoil, you can use the HATIS with that or a neck loop. You can also use your personal audio cable.

AUDIENCE MEMBER: Do you notice that music is better using the HATIS or doing direct?

KATHY ALLEN: I personally feel a HATIS is much better than a personal audio cable because the HATIS sound is better. I can also use the HATIS bilaterally with both of my implants. I also like the neck loop because that sound is very clear and more stereo

sounding and I can use it with two implants. These are my personal opinions. I encourage you to try different devices and see what you like best.

AUDIENCE MEMBER: Which neck loop do you find works the best?

KATHY ALLEN: There is only one neck loop I like for listening to music, the Clear Sounds neck loop. It has an on/off switch, and on the bottom, you can adjust the volume to meet your needs. You can get this neck loop for about \$100 from HiTech.

AUDIENCE MEMBER: Or \$60 from Walgreen's, online.

KATHY ALLEN: The beauty of Clear Sounds is it also comes with an adapter to use with I-Pod or audio devices. You take that adapter off and you can use it with a cell phone. It has got multiple uses.

AUDIENCE MEMBER: The HATIS set that I spent a bunch of bucks for has a Walkman size plug, but with a six dollar adapter from Radio Shack, I can plug it into my cell phone, too.

KATHY ALLEN: The HATIS is very expensive, about \$139 for a single side or \$160 for two. The music one alone is about \$99. It does work well, We also have something called a NoizFree which is a little cheaper, about \$50. It is available from Harris and HiTech. You can also Google NoizFree and get a list of places where you can get it. It has a smaller silhouette that you place behind your hearing aid or cochlear implant. Put your device on telecoil and then plug the end into your I-Pod. If you get the one for the cell phone, you can buy the little adapter for about six bucks. So these are great devices that work off of your telecoil when listening to music.

HATIS has Mach I Epic for music. It cannot be used for the cell phone. It costs about \$99.

Now, how do you get started in listening to music and enjoying it again? First of all, if have a memory of music, you want to choose simple and familiar tunes. Think about a song with one singing voice or one type of instrument if that is what you are interested in. Get the printed copy of the lyrics to follow along.

If you have limited experience with music, begin with some children's tunes or holiday songs. Choose simple tunes with a strong beat because the beat can guide you through this tune.

Create your play list. Find the songs that you really enjoy. You can try songs for free by going to the I-Tunes website. There I-Tunes will play a short burst of a song so you can see if you like it before you buy it. Also go to Border's or other bookstores that have music you may listen to on headphones.

Another thing about lyrics is CDs sometime print lyrics inside the covers or the box. Go through your old CDs and pick out tunes that you like and are familiar with. So create a play list that you like, that is familiar to you. Or even create a play list with songs you don't know but enjoy. Jazz or rhythm and blues is very good for practice listening to music again.

Remember; don't become frustrated if you can't hear the words. It can take time. I hear the words and music if I have the lyrics or if I know the lyrics. But just driving down the road and listening to the radio in my car and hearing the words to music just doesn't happen.

If I know the song, I can sing along. Always have those lyrics in front of you. Listen to some of your old favorites over and over and over again. You will be surprised at how good the sound quality will improve over time. Ask a partner to sing along with you so you can lip-read them and learn that placement of the words.

Practice tips: Remember to listen to music when you are fresh and in a good mood. Dance if you want to. Dancing helps you get a feel of the rhythm. Go to the karaoke bars. You don't have to sing, but following the lyrics on the screen is helpful for improving your singing voice.

Remember, music appreciation takes time and effort. Accept that music may never sound the same as you remember. Choose music you are familiar with. Experiment with different types of music. Experiment with different accessories. Try the different settings on your cochlear implant or hearing aid. If you have noise reduction programs on your hearing aid or your implant, try that. Sample the songs before you buy them. Print out the words to the music and ask a partner to sing along with you. And finally, one thing I want you to take with you from today is what I call the four P's -- patience, persistence, practice, and a positive attitude.

If you have the four P's, you will go far. Not just with music, but with any kind of hearing aid or cochlear implant and in life in general. So with that, I would like to thank you for your attention today.

AUDIENCE MEMBER: I find that if I just mouth the words along with the song or whatever I am hearing, I understand it better. It is not necessary to use my voice but mouthing helps me integrate the sound in the song more.

AUDIENCE MEMBER: From your experience, would you recommend using headphones as opposed to a loop?

KATHY ALLEN: I prefer using the loop. I also do just as well with the headphones. I have even used those little bitty headphones on an airplane. As for big headphones, I especially like the Bose or the Sony, but the neck loop is not cumbersome. I don't have to carry big headphones. It is easier for me, and I really do get the same sound quality.

AUDIENCE: What about concerts? How do you fare at them? Do you go to concerts?

KATHY ALLEN: Yes, absolutely. I went to two outdoor concerts this summer. I was surprised when I went to an outdoor concert of someone I didn't know and I had never heard before. My intention was to take the time and listen to her music before I went, but I just never got time. It ended up being Diana Krall and this guy named Chris Botti who had the most incredible voice I ever heard. I did well. There weren't a lot of words to the music but I could really hear the pitch of the voice. I could hear the beat. It was really a very nice experience.

First, I thought outdoor concerts, no way, because there is so much background noise and people talking in the crowd. I just used my cochlear implants, nothing else, and it was fine.

AUDIENCE MEMBER: One of the biggest fears I have about getting a cochlear implant is the changes in music that I have always heard and been accustomed to from wearing hearing aids. I played the piano as a kid for many years but I haven't played for a long time. My oldest plays the piano so it is lovely to hear him play, but I fear if I were to get a cochlear implant, that music would sound different.

KATHY ALLEN: I remember thinking with my hearing aids, I can hear music, but I am losing that ability. Will music sound good? When I first got my first cochlear implant, music was horrible. Then, I wore my hearing aid on one ear and implant on the other the ear. I kept listening to music over and over and it got better. Then I kept hearing from people who had two cochlear implants that music was even better.

I said, "Great. I got to get two." I based my cochlear implant decision on music. I didn't care about anything else. I got a lot of music, though with one. I got two cochlear

implants and music was awesome. People were not lying to me. It was stereo.

Did it take work? Of course it did. I had to listen with using both implants together, but music was great. There are so many great benefits with a cochlear implant, not just with music but also in life and communication and social gatherings especially if you have kids. I want you to think about what you are missing by not being able to hear really well right now. Not just with your family, but with music and in social situations and all of that.

I know it is really scary to think about how bad music may or may not sound. But how are you ever going to know if you don't take that leap of faith and try.

AUDIENCE MEMBER: I got turned down.

KATHY ALLEN: your insurance company turned you down for a cochlear implant?

AUDIENCE MEMBER: No, by the audiologist.

KATHY ALLEN: In that case, I encourage you to have another evaluation and make sure your evaluation is at a cochlear implant center. The evaluation has to be by a cochlear implant audiologist, someone who specializes in cochlear implants.

AUDIENCE MEMBER: I am wondering if there is anything tactile. I use a balloon in my hand live concerts.

KATHY ALLEN: That is a good idea, a very good idea. If you go to a very good concert and sit next to the speakers, you will have tactile information. You will have body information. Everything will shake so ... you know.
All right, well, thank you for your attention today.

Kathy Allen, MA is a bilateral cochlear implant recipient and Senior Awareness Manager with Cochlear Americas. She holds a Masters Degree in Counseling from the University of Illinois. Kathy was born with a severe to profound hearing loss & received her first hearing aid at the age of 5. Despite her hearing loss, Kathy developed a love for music at a young age, often listening to records while her sister wrote down the words to songs & lip-synced so she could learn to sing along. Throughout her school years, including college, Kathy played the Oboe, Saxophone & Drums while performing with concert & marching bands. At the age of 38, she received her first cochlear implant and continued to enjoy music by utilizing the implant and a hearing aid together. In April of 2005 Kathy received her 2nd cochlear implant and states that music sounds better now than it has her entire life! Her favorite musical instrument is the harp.