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TO CI OR NOT CI: THAT'S THE OPTION

PANEL DISCUSSION

Presenter: Robert Alpern

ROBERT ALPERN: I was born hearing and my hearing loss gradually progressed throughout my childhood years until I was left with profound, severe, binaural sensory hearing loss. I first found about cochlear implants at hockey camp for the deaf that was established by the Hall of Fame hockey star Sam Mikita. I am now a candidate for cochlear implant. Many of my peers use a cochlear implant at R.I.T., and the National Technical Institute for the Deaf.

JEAN SPENCE: I grew up in Michigan and moved to Rochester about 22 years ago. I do have a cochlear implant. I started losing my hearing when I was about 18, and by 20 I was profoundly deaf. I received a cochlear implant in 1986. I don't use it today but I did use it for 17 years. I learned sign language and came to R.I.T. I received another cochlear implant in 2003 in the right ear; Esprit 3G. But I don't use the old one any more.

DR. ROBERT MENCHEL: I was born in Albany, New York. I became deaf probably around 6 or 7 years old, from spinal meningitis. I spent a year or two in Albany and grew up deaf. Then I went to PS 47 in New York and back to Albany for high school. Then I went to college from there. I have a CI, got my CI when I was 68 years old.

WILLIAM RAE: I started to lose my hearing at age 7. It was a progressive loss. Never really used a hearing aid until I was close to 30. I graduated from R.I.T. with a BS in 1967. I worked 31 years for Kodak. Right now I'm living my dream, retired. I have a part-time job playing golf and I have fun teaching.

LANE LUCHT: I'm originally from East Central Minnesota and have a profound sensory bilateral hearing loss. I have gross speech discrimination with hearing aids to help me hear better. I'm starting to go deaf because I'm getting older and have worn hearing aids since the age of two or three. I was born deaf actually. I went to the Minnesota School for the Deaf for many years and then went to mainstream. Currently I'm at R.I.T., pursuing a degree.

SALLY SKYER: I was born profoundly deaf. I have about 100 decibel hearing loss. I also have a deaf brother. My husband was late-deafened. Three of his sisters were late-deafened. I am from Rhode Island. I have been working for 29 years working as a counselor at National Technical Institute for the Deaf.

ROBERT ALPERN: I would like to open up questions for those without cochlear implants. Would you briefly state how long you have been using hearing aids?

SALLY SKYER: Since the age of 2, only during school hours. I wasn't allowed to wear it outside of home.

LANE LUCHT: I have worn hearing aids since I was two or three. When home alone I prefer not to wear them.

WILLIAM RAE: I didn't start wearing hearing aids until I was 26. I've been using them for 37 years.

ROBERT ALPERN: Also I would like to know for the non-cochlear implant users, have you considered getting a cochlear implant? Why or why not?

SALLY SKYER: I did consider getting one and I was curious because the more I talked to my friends about cochlear implants, the more curious I became about what people were able to hear and able to benefit from the cochlear implant. But I would talk more, ask a lot of questions. I went through testing and evaluation and was approved for getting a cochlear implant. I was just about ready to go for the surgery when my daughter had her own surgery and I held mine off. As a result of her surgery related to tumors, she became completely deaf. So that changed my position because I didn't feel that it would be fair to her for me to be able to hear more than her. And I chose not to pursue the cochlear implant as an option out of respect for her even though she encouraged me to get it. My husband encouraged me to get it. I chose not to. And also the more I would talk with people I would hear about the noisy environment, noisy world and I thought, it is not worth it. I've been used to not hearing noise. Like the birds or the cats, I'm just used to it. I didn't know what I would miss and I like my quiet world. I like it. So it is my decision and I'm happy that I didn't pursue that path. Maybe it will change later. I am open to that option.

LANE LUCHT: I'm still considering getting a cochlear implant probably because -- I don't consider myself disabled. I like my quiet. But at the same time, like I said earlier, I rely on my residual hearing to help me lip read, and because probably I'm getting older, I'm starting to lose what residual hearing I still have left. It is becoming harder for me to lip read and interact with those who are not deaf or hard of hearing. Part of my background is to stay involved in the hearing world. And so I find myself open to possibly getting a CI especially for my left ear. Apparently in the past year I lost all of my useful hearing in that ear. Up until then, I thought why get a CI when hearing aids could help? And also, I would rather wait and see, observe other people who have CIs to see if it actually benefits them. To me it's not important to be able to hear the crinkling of toilet paper. To me, if I spend all the money on CI, I want some meaningful benefits, and by that I mean easier interaction with those who don't know sign, with those who talk, and to be able to enjoy classical music again.

WILLIAM RAE: I feel much of the opinions that Sally and Lane have stated. But maybe 10, 12 years ago the audiologist and doctor approached me as a candidate for a cochlear implant. I asked the doctor at that time how much of a chance do you promise me for improvement, and he said, "Well, I can maybe promise you five percent." I said, "Five percent? That's not enough. Can you promise me I will be able to hear music, the words and music?" He said, "I don't know." Now, I realized that's 10, 12 years ago. But I made the decision then that CART works, for both money and time, and I could not justify the benefits of a CI. Another thing, I don't want to depend upon something and have it break down. In the future, what if something better comes along and I already have a CI?

ROBERT ALPERN: I would like to ask some questions of the cochlear implant panel. Jean, why did you decide to get an implant?

JEAN SPENCE: When I started to lose my hearing I got a hearing aid for two years and it stopped working. There was no hearing aid that would work enough to help me. So I went to the **House Ear Institute** in California and researched the cochlear implant, in 1985. When I went there to check it out, I came back with an opinion, no, this is not for me. I wasn't interested. Then as time went on, a short time, about nine months, I decided to go ahead and get the cochlear implant. I thought I had nothing to lose, nine months living in a deaf world, and I was okay but I really missed hearing. So I thought I would try it if I get any kind of benefit that would help me. In 1986 I went ahead and did get the cochlear implant and had the training. The surgery was different at that time and the technology was different but I was able to benefit from it greatly. My sister wrote a paper about how I changed from when I didn't have the cochlear implant to having the cochlear implant. There were things like, I was

more outgoing. My speech was better. I was clearer. I was more assertive. Less fearful, and what I liked about the cochlear implant at that time was I had a choice to wear it or not wear it.

In 2002 I wanted to update my cochlear implant. I struggled with that decision and decided I wanted to implant my opposite ear. I didn't want to take out this one because I was afraid of going through another loss. If they took it out and put another one in, I was afraid it might not work and I would be left with that one time chance of getting some kind of benefit. So I made my decision and thought it through very carefully. I wanted my opposite ear implanted and they agreed with me but told me. "You have not heard in that ear for 20 years and are not going to do well." I just said, "Trust me; I want to do what I want to do. It's my ear. Let me make that choice." With the benefit of the newer implant technology and I stayed with the same cochlear company, I got a new and improved smaller processor. I was thrilled because I didn't have to wear the behind the ear and the box and the wire. It was just one little piece. In the beginning I didn't hear well but as time went on I heard a lot better and I got a cell phone and my speech was better. I found myself opening up even more to my world, and to the hearing world, too. For me it's a choice. I can wear it or I don't have to wear it. That's what I like. I like my silent world, too. I'm not afraid to take it off but I do enjoy the benefit of hearing.

DR. ROBERT MENCHEL: I will give you my background first because we need to understand where I'm coming from, why I decided today get a CI. As I said before, I never really used a hearing aid. My world was one of total deafness and somehow I was comfortable. I went to Hudson Valley College for support. I went to Clarkson for my BA for support in the classroom. I got through it, not easy. Twenty years later I went to R.I.T. to get my MBA. Now I had some support and I had an interpreter. I realized how much of the classes I had missed back then. I said to myself that I was really missing an awful lot. Later when I went on for my doctorate, I wanted all the support I could get and got it.

My life has been going from not really knowing to now being fully aware what I can get and I am comfortable with myself. I have four children, never heard their voices and five grandchildren, and never heard their voices. My wife is in music and she loves music. We have five speakers, musical speakers but I can't hear anything from them. I didn't want to have a wire and something there. I had self-pride, didn't want to have people seeing this equipment. I was thinking: what do I get out of it? I was aware of people wearing CIs and I talked to Bob Frisina at N.T.I.D., and some other people. Then I went to see the doctor and he said he wasn't sure. One of the things about my deafness was that the bone may have closed off and the surgeon would not be able to put the wires in. I was 68 at that time. The doctor wasn't quite sure.

They never had anyone with my degree and kind of deafness to get implanted. They weren't sure about the results but they tried. They and I did not expect very much. I would be satisfied if I could hear the environmental noises around me. Maybe if my wife called me, I could hear her calling me. Small things, I did not have high expectations, but I could hear even if it was very limited. I did not expect to be a hearing person. When I turned it on, I got much more than I expected. I'm comfortable with it now, too. It makes me more of a deaf person. People see this and recognize I am a deaf person. Before when I had nothing on they wouldn't know. Last night I went to the theatre and they had brass music which I heard. I enjoy my grandchildren. Every year I'm discovering more and more what I can do with my cochlear implant. I don't take it off until 11 o'clock at night and my world is quiet. So I feel very comfortable with it now.

ROBERT ALPERN: What are your biggest concerns, personally, or hesitation when getting an implant? What were your expectations at the same time before getting that implant?

JEAN SPENCE: For the first time one in 1986 I had concerns that I wouldn't get any benefit from the cochlear implant. That was my major concern. The second one was that nothing would change if I didn't take that risk, really. And I had my whole life ahead of me. So the second time around my concern was, again, that it might not work but at the same time I'm a high living girl and I thought I want to try it again. Today I say if I had a third ear, I would do it again. I have faith that I would get some kind of benefit out of it. I have an 11-year-old son and I wanted to hear him better, more clearly, and the CI benefited that.

DR. ROBERT MENCHEL: I agree with you. I said to myself, I have nothing to lose, nothing to lose. But an interesting thing is that you must remember way back in 1961, the CI had two wires. I said no, "I'm not going to get on the table for that. No way." Today, with 21 wires, they say nothing to lose and a lot to gain. But I, and maybe other people, go into this with high expectations. We need to be realistic about it.

SALLY SKYER: Speaking of fear, my fear was brought about by expecting too much, hearing more than I want to hear or hearing things that I don't want to hear. That was my fear. Because the more I talked with people, what they were hearing, toilet paper ripping, I don't want to hear that. A dog walking with claws, I don't want to hear that. I don't want to hear other people farting or different things. For me, I would be hearing more than I want to because I have grown up 56 years hearing very, very little. And I'm not unhappy about that. Sure, it is a frustrating experience with communication but I have lived with that, handled that, coped with that and I'm okay with it.

ROBERT ALPERN: Did anybody else have something to add?

LANE LUCHT: When the CI first came out, people were talking about it and then about two or three years later I found out that the rate of success was shockingly low. When I heard that, I was furious because I felt that all these doctors just want to mutilate and never once did I hear about the risk of facial paralysis and hearing loss after surgery. Once you have had the surgery, you can't take it out and wear hearing aids again. But I just cannot get over this. Recently, I noticed more and more students at R.I.T. with CIs. I think that's great. At the same time I have noticed quite a few of them having massive scars, very visible covering all the length of the head. And I thought, what is this, more mutilation? My CI is visible enough and people react when they see the scar compared to only having hearing aids. Not a problem. But they see the scar and people shy away from that.

DR. ROBERT MENCHEL: First, when I got the CI, I couldn't wear it all day. It was too noisy, too much. I had to take it off. Today I'm more comfortable with it, and I use it in my environment, turn it down, and turn it off. Last night in the theater, it was up. Of course, I wanted to hear music and pick it up. The sound was up. But when I got home, I turned it down, quite comfortable. I have learned how to deal with it, and to say yes. There are times when I turn it off, too noisy. I have the choice.

SALLY SKYER: I hear from people about the emotional impact the CI has on them. One particular friend was going through a very difficult adjustment being able to hear after the realization about what she had missed all those years when she didn't hear. The emotional impact it had on her is something I don't want to go through. It is my choice.

ROBERT ALPERN: One last question for the cochlear implant panel. Can you give an example how the impact of sound most surprised you after you went through the surgery?

JEAN SPENCE: One of my favorite things happened when I took my son shopping at Kmart. We were in the toy section and he asked me to get a toy and I said, "No, that's not what we are shopping for right now. Let's move on." Well, he had some snotty comeback and said, "Oh, Mom, you are just so mean." I said, "That's not acceptable," and he looked at me and said, "You heard me?" I hadn't looked at him. I had turned around and I heard what he said. I can have a conversation with my son in the car when he is sitting in the back and I'm driving. To me that's a miracle. I never expected anything like that. I could use a cell phone; talk with my family for an hour. Clearly I can talk with friends, make a call to the doctor for an appointment; fill a prescription medication and a lot more. I never liked to use the phone even when I could hear. Those things are big. I like to listen to music in my car from all these to new CDs. I never thought I would listen to music again like that. I can sing along and I dance in my car, too.

Those are really big things for me. I have to comment though that I was never given advice about the cochlear implant, like you should get it. Over 22 years of watching changes in the cochlear implant, watching more people get it and a lot of conflict in the deaf and hard of hearing community, I needed to watch all of this. I was one of the first few thousand at the beginning who had the cochlear implant and I came to Rochester with one of the largest deaf populations. In the beginning it was emotionally hard because I knew there would be some rejection there or some misunderstanding about the cochlear implant. Sometimes I would be able to speak out and just share only my experience. I made a good decision and am still glad I made the decision to get a cochlear implant. I didn't mutilate myself either. I can only speak from my experience. I'm glad that I did it, and if I had a third ear, I would do it again.

DR. ROBERT MENCHEL: It is hard to say. I think a lot of it surprised me. I was very dependent on lip reading but that really improved a huge amount. I noticed that lip reading has improved without it. With the CI is a big difference. When I first got it, I asked my wife what some noises were. So those things surprised me. It has been a learning experience. Now that I am getting some training, I'm beginning to be able to see the difference between different sounds and different words, like "sh," "th," "ing." My mind is waking up now. It has been quiet a long time since I heard. I was a baby having to learn all over again with the CI.

ROBERT ALPERN: I'd like to ask some questions of the non-cochlear implant users. What advice do you have for people feeling pressured to get a cochlear implant?

WILLIAM RAE: I think the key word is we have a choice. I will explain two things. One thing I learned is that I like many things. It's what you expect. Bob has said he didn't have high expectations. So he could probably be a most satisfied user.

Also, I noticed a lot of students and some adults on campus, who have had cochlear implants, do not use them. Why?

LANE LUCHT: I would emphasize to the person, it's a choice. It is your decision and you need to find out as much information as you can about CIs. Talk to people who have expectations and make sure you are doing it for yourself, not for the doctors, not for the educators, not for anybody else, just for you.

SALLY SKYER: Collect as much information as you can from a user and a nonuser, from someone who liked the CI and someone who doesn't like the CI. Get a balance of information from people who are pushing the CI, and who are not and from people from a range of experience to help you make the

right choice. I was pushed into thinking that I would benefit greatly from it. I had to rethink that push. I resented that push.

ROBERT ALPERN: What do you recommend for someone considering an implant?

JEAN SPENCE: I agree with what Sally said. Get as much information as you can. Talk with a variety of people who have the cochlear implant and who don't have the cochlear implant. Listen to the medical part. Get good information, reliable information, not from someone on the Internet. Pray before you make a decision. Then listen to your intuition.

I was married to someone who decided not to have a cochlear implant and I completely respect that decision. To live in the same household with somebody who didn't want to have a cochlear implant, cochlear implant wasn't the issue. It wasn't the big issue. But I think just to get good information and listen to your own self.

DR. ROBERT MENCHEL: I agree. It took me several months gathering information, talking to experts, and other people who had the CI. I looked at the different models and what was available. One of the important things is that you need to realize if you have a CI, you can't have an MRI. The one I have can be removed if necessary. Things like that are important for you to know. Don't let anybody pressure you into it. Take your time. Think about it and talk with people.

LANE LUCHT: I'm just being the devil's advocate; all that is fine if you will be making the decision yourself. What about the parents of their deaf child? I don't know.

ROBERT ALPERN: I would like to now open up the panel for questions in the audience, if anybody in the audience has any questions.

AUDIENCE: You mentioned if you have a CI and you can't get an MRI?

DR. ROBERT MENCHEL: Most CI's are not removable. The model CI I have is removable.

AUDIENCE: By removable, do you mean they don't remove the implant, just make a tiny incision and take the magnet out and put it back in? They're not taking the whole implant out are they?

DR. ROBERT MENCHEL: There are different models. In some of them, the transmitter can't be removed. The one I have can be temporarily removed. It can be put back after.

AUDIENCE: I'm deaf in my left ear and in my right ear my word discrimination is very are poor, between 60 and 80 percent. I've been trying to get a cochlear implant for my left ear. I have been to three different doctors who won't recommend it and the insurance companies will not approve it. To me

it doesn't make sense that I cannot get a cochlear implant in my left ear because I'm deaf. Can anybody help me?

CATHERINE CLARK: Part of the cochlear implant criteria is looking at your hearing levels in each ear. Typically the recommendation is pure tone average of 70 decibels or higher as well as the word discrimination ability, looking at your discrimination on sentence tests. Scores may range from 50 percent or higher, and sometimes with quiet and sometimes with noise. I think in some places some people would consider you a candidate in that opposite ear.

I have some audiology colleagues in here and just nod if that's correct. They are nodding. I'm not sure why at your center you are not a candidate. There may be variables involved. The anatomy of your cochlea is a variable as well. I'm not sure what criteria your insurance company is using to determine that you are not a candidate. Without having that information I'm unable to answer that question for you. You always have the right to get additional opinions. You may not be a candidate in one place and may be in another place.

AUDIENCE: First of all, the only place to really understand if you are a candidate for a cochlear implant is at a cochlear implant center. They don't just put it on everyone. They turn people down. If just your medical doctor or ENT in your town are saying no, you are not a candidate, that's really hardly anything to go on. A small one or two hour discussion can get an evaluation from an implant center.

Secondly, if you are calling your insurance to just see if they'll pay for it, people who you talk often don't know what a cochlear implant is. The cochlear implant center people know about what medical terminology to tell your insurance company. You probably will not be turned down if a doctor gives the medical terminology to that insurance company. The implant center is the place to go to.

One more comment about having one deaf and one hard of hearing ear. Implant centers do implant either ear at your choice, usually. In my case, they were going to implant my deaf ear which has been deaf all my life. I wanted them to do the hard of hearing ear because that's where my brain learned language and understands it. The deaf ear never understood speech. The very first day they turned on my implant 12 years ago, I understood every word up to 90 percent, a very rare thing. I feel had I implanted my deaf ear, it would have taken a lot longer.

AUDIENCE: I just had an interesting experience. I got implanted in my left ear which went from 90 to nothing at all decibels. My doctor was going to put it in my right ear which has not heard since I was 3 years old. Nevertheless, they put it in the left ear and I did pretty well. Last year I decided I'll get it done in the right ear. My doctor okayed it, insurance okayed it and no problem. I've had it for a year now

and I can hear a lot and it sounds pretty good but some things are still muffled. I'm still learning and it will take longer to get up to where this left one is. It is an old ear that hasn't heard and there is still memory somewhere but it takes a while longer to make it work.

AUDIENCE: I've had a cochlear implant for five years now and I've been deaf since the age of five. I decided to have a cochlear implant because my hearing aid did not help me any more. I want to tell everybody if you are thinking about it, yes, no, back and forth, you only live once. You may not have tomorrow. But if you are thinking of having one, don't wait. I'm very happy.

ROBERT ALPERN: Thank you very much. I thank everyone for coming today.

Robert Alpern is graduate student in Mechanical Engineering at Rochester Institute of Technology. He is specializing in biomedical medical engineering and previously co-op with Johnson & Johnson and Merck Co. His interest in cochlear implants extends to his childhood and he interacts with many peers who use Cochlear Implants.