



Transcript of meeting: Saturday, October 20, 2018

This is an edited version of the transcription projected on the screen during the meeting. The transcriber used the "TypeWell" method synthesizing the essence of the discussion using advanced abbreviated software. Thus, the following is not necessarily verbatim.

"New Technologies Beyond Hearing Aids"

This meeting included a panel discussion with group interaction.

The Panel...

Nicole Brent, Cochlear Americas Engagement Manager, Moderator

Douglas Sladen, Ph.D., Assistant Professor, Western Washington University,

Claydene Lederer, Spouse of cochlear implant recipient,

Jerry Finkbonner, Cochlear implant recipient, a bi-modal user (CI one ear; hearing aid on the other),

Joanne Boschman, Recent cochlear implant recipient

Nicole: Thank you so much for having me today at your meeting. My name is Nicole Brent. I am the Engagement Manager at cochlear. That just means that I have the privilege of working with both people that are learning about cochlear implants and those who have cochlear implants in the hearing loss community.

Today we have a special treat for all of you. That is the opportunity to hear from your peers. So sitting up here today with me are four very incredible individuals who will plan to share their experiences and thoughts with all of you.

If you would like additional information about cochlear implants, I can follow up by email or telephone. Please do not hesitate to contact me.

nbrent@cochlear.com. (206) 753-9054.

Before we start with questions I would like each of the panelists to introduce themselves and tell us how they are connected to cochlear implants.

Joanne Boschman: I am 79 years old. I was born deaf. I suffered through school. But

my parents were very good, and they went up and talked to the teachers so that the teachers and principal was aware I was deaf.

I got through elementary with no problem. I went through high school as well. I did it without hearing aids. When I started to go to business college I got my first hearing aid. It really did help through college. When I graduated I worked for the Vancouver Sun for the advertising department.

I got married and raised children. Our first son was born with hearing problems. We decided to adopt our other two children. They are all grown up now and are married and have children. I have four grandchildren. Luckily the deafness has not gone through to my children.

In the last few years I have attended these meetings. Pam introduced me to cochlear implants. She suggested Dr. Westerberg in Vancouver to be evaluated. I was busy golfing and living, I went through the tests and was accepted but I didn't get one. Ten years went by and I was badgered by Joan and Bert to get a cochlear implant.

I decided to get one. I went ahead, and I am so happy with it!

Dr. Sladen: Hello, I am Doug Sladen. Important thing first, I am also Canadian. I am from a small town in the interior. I have been in the states most of my adult life. I received my masters degree from Western Washington University in 1994 and PhD from Vanderbilt in Nashville in 2006. I am the former director of the Cochlear Implant program at the Mayo Clinic.

My interest in cochlear implants is multidimensional. I have an interest in research. I do studies on how people perceive speech through implants. I have an interest clinically, I have seen the impact implants have on people's lives. I want to spread the good word about the positive impact.

Thank you for having me here.

Jerry Finkbonner: Hello, I have lived here all my life. My great, great grandfather migrated from the Black Forest of Germany and came to the US through Ellis Island. He was here when the tribes signed the Point Elliot treaty and married the chief's daughter. If you have been here in the county for a while you know the Finkbonner name. There are 400 of us around here. I am a tribal member with the Lummi nation.

Most people don't know Finkbonner is a German name! I started teaching with Ferndale School District in 1978. In 1990 I got a viral infection in my left ear which killed the inner nerve. I couldn't hear anymore. I should have gotten a hearing aid, but I think I showed vanity which stopped me. I went for 26 years just hearing in my right ear.

I have two sons in their 20s. I retired from teaching in 2013. On July 18 of 2016, I went to bed feeling fine and woke up at 4:30 and I was basically deaf in my right ear. I had a loud roaring sound. I went to the hospital and did all the tests. Nothing showed up. I was told that I was one of those one in a thousand chances where there was no explanation.

I ended up using Phonak hearing aids. They just didn't do anything. I qualified for my cochlear implant on my left ear in November of 2016 and they chose the left ear because that was the one that had been deaf for 26 years. They found that the implant would have a better chance in my left rather than my right which had just become deaf.

It opened a whole new world to me when the cochlear was activated. We will talk about that later.

Claydene Lederer: Hi everyone! I am a hearing person! I hear so well that when Bert is on the phone I hear both sides of the conversation. I have lived with Bert for almost 60 years. He has gotten progressively deafer. I was an expert at saying "never mind" after asking him things over and over. It got so frustrating dealing with him.

In 2006 we were at the Olmsteads and Jerry said, "You idiot, get a cochlear implant!" We went to the HLAA convention in Reno. We met Linda Day, the Cochlear rep. After much discussion, Bert was convinced, and he received his cochlear implant. Living with him has changed dramatically. I will go into that later.

Nicole: Before we get into responses, let's talk about the actual cochlear implant. I want to turn it over to Dr. Sladen to explain what this does and how benefits from having one.

Dr. Sladen: When hearing loss begins to emerge there is damage to those tiny hair structures inside the snail like structure of your inner ear. First making it sound louder is OK. There are enough remaining cells to stimulate. When the damage gets severe the hair cells deplete. Making things louder doesn't help. That is when people become candidates, to bypass that level of dysfunction.

The results are outstanding. Way more than we could have expected. The way it works is that you wear an external piece with a microphone and a battery and a processor and a transmitter. Sound is picked up and coded in the processor. That information is then sent to a transmitter which sits on the back of the skull. That transmitter sends that information and the power of the internal device across the skin on a radio frequency. When I say it out loud it strikes me as incredible.

So, this is sent down to an electrode, a wire, sitting in the snail like structure. Out of that comes little bits of electrical current. Just enough to make the fibers fire. If you put an electrode on your hand you wouldn't be able to feel the current coming from it. It is

a very small amount of electricity. But it is enough to make a neuron fire.

A cochlea is arranged like a piano. When you put contacts at the bottom you hear a high pitch, on the bottom you hear a low pitch. It is not like hearing when we had normal hearing, but it is enough to hear in quiet and in noise.

Nicole: Thank you for explaining it. So, the cochlear implant is not natural hearing. A question I hear is, "What does it sound like to hear with a cochlear implant and how does that change"? Can you address that Jerry?

Jerry Finkbonner: We have chosen to do this in the left ear, where I hadn't heard anything for 26 years from that ear. That side of my brain was not used to sounds. Once I did have the cochlear activated in early December, there were a couple of weeks for healing to take place, I could hear for the first time on the left. I couldn't hear on the right because I had gone deaf.

I have heard that people hear normally right away and other people have more adjustments. Mine was a situation in which every voice I heard sounded like Daffy Duck. Which was funny. I love Daffy Duck. But I don't want to hear everyone speak like that to me!

So that basically made it more difficult to hear because of what people sounded like. I won't try to imitate Daffy. You can probably remember him! It took me a long time, a good six months, before I could distinguish between voices. I will talk later about how we did that.

As I said earlier, my life has improved 85%. Or more. The cochlear implant was the biggest change for me. The voices are getting much better.

Claydene Lederer: When Bert was first turned on --- when his implant was activated I was in the room with him at UW Medical Center. He had his hearing dog there, the first thing he heard were the dog tags. Warren stood up and shook and he heard the dog tags. It makes me cry to this day. Bert heard speech normally and well. It was the sounds that he hadn't heard for 50+ years. We live in a noisy world. Things that he hadn't heard were birds. Were motors. Were the ice maker dropping ice in the fridge. The coffee pot gurgling. We spent a whole year with "what's that?" Some days it was exhausting. We could communicate very well but it was the sounds.

So, my favorite, which is embarrassing for him, was the day he walked down the hall after being in the rest room. He had a silly smile on his face. I said, "what's wrong?" and he said, "ow I know why you call it tinkle." He did not know that when you went potty you could hear yourself pee!

Nicole: Another question that I get a lot from people who are considering an implant is

related to the surgery. The actual procedure takes less than two hours and is an outpatient procedure most of the time. That is done with general anesthesia. It doesn't seem as invasive and some think.

I know that people have concerns around surgery. Joanne what were your concerns?

Joanne: I really wasn't concerned with the surgery itself. That part didn't bother me at all. But the thought that the period of time before the surgery when I just had my left hearing aid and the right was gone, that was a difficult six weeks. All of a sudden, I didn't want to go out. I couldn't hear properly. I didn't realize how important that right hearing aid was until it wasn't there.

So I really was worried about it working. I couldn't imagine it being like this the rest of my life. So it was funny, when I went in the surgery I was lying on the trolley and one person would come in and talk and then another and then Dr. Westerberg talked to me, I mentioned that I needed to use the bathroom but then someone else came in. Before I knew it, they were wheeling me up to the OR. Everyone was all gowned up!

Dr. Westerberg asked if I had concerns and I needed to go to the bathroom! There was no restroom there. So they had to wheel me back down the elevator. I got to use the washroom and then wheeled back up! When I got back up there everyone stood and clapped. He said, "Well now are you ready?". It made me relax for the surgery so much.

Nicole: I think a lot of people may be sort of straddling hearing aids and cochlear implants. I want to hear about what that instance was, or the situation was that occurred that made you make that decision to move forward to have the surgery.

Joanne Boschman: I had waited 10 years from when I was first approved to when I was ready to get it at 78. It was time.

Jerry Finkbonner: For me, because I had been deaf for the 26 years on the left, but my right was acute -- in fact I explained to new students that my left was deaf, and I needed them to come to my right side. Inevitably I had high expectations in the classroom. When it was work time, I could pick out which students were socializing. I would remind someone it was a work period. Students would always say, "I thought you were deaf in one ear!" The right ear took over!

In July of 2016 when I became deaf in my right, I had hearing aids in both ears. It was no more than 20% hearing because of the type of hearing loss I encountered. From July 18 to the middle of November having those two hearing aids was basically, "Is this all there is to the rest of my life?" I couldn't live like this. I couldn't hear 20% for the rest of my life. When I took them out I only had 5%.

I thought I wouldn't qualify for a cochlear implant, but I did because of the type of

hearing loss I experienced. It was an easy decision for me. What I had was basically nothing. Maybe 20% hearing. With the cochlear implant I had hope. I have not regretted that decision at all. As I said, I figure I have at least 85% hearing with that left ear. What I had was basically worthless.

Claydene Lederer: I would like to speak to the fact that the surgery is now so much less invasive than when Bert had it in 2008 at the UW Medical Center. He did not recover well from surgery. There was trouble with the breathing tube and too much anesthesia. When we hear the miracles of today, it is in and out! He was in the hospital for two days and suffered with a large incision. It is a miracle today at how fast and effective and quick it is!

Don't be afraid of the surgery!

Mike: I have a question. I am curious, Joanne, did you have the implant in the U.S.?

Joanne Boschman: I had it at St. Paul's in Vancouver. It was very simple. The opposite of what Claydene was saying.

Jerry Finkbonner: I was also in and out. But everyone is different. The only problem was that you leave with your head wrapped and bandaged. You look like you were in a terrible automobile accident! Then after about a week you take it off. There were three weeks before it was activated.

We have come a long way since 2008. But people react differently to anesthesia.

Nicole: Dr. Sladen what do you tell them before the surgery? What do you tell them about expectations?

Dr. Sladen: I will echo what everyone said. It is less invasive than it used to be. The surgeon makes a small incision behind the ear, pull back skin, drill through bone, when they get to the inner ear they make an incision, slide the electronic piece under the skin and then sew it up. If you were to ask a surgeon about this surgery, they would tell you that it is considered less invasive. You don't need a blood transfusion because you don't lose enough blood.

You have to be intubated and under anesthesia. It is pretty straight forward from the surgeon. Placing the electrode takes skill and experience. There is about 1% of patients who have side effects like dizziness or vertigo or pain, but it happens infrequently. The symptoms tend to resolve quickly, within 10 days.

There is a smaller number of patients who have a permanent problem with dizziness after the surgery. This is a rare occurrence. Patients expect to be out the same day and expect to be back to feeling good about themselves within a week. They will not be

allowed to lift more than 25 pounds for a week. They are advised not to fly for a few weeks, but that is because of the pressure changes. The healing happens relatively fast.

Jerry Finkbonner: If you are thinking about a cochlear implant, we used to have to travel to Seattle or Vancouver, B.C. We are fortunate to have Dr. Olson who performs the surgery here in Bellingham. It is done at St. Josephs. This is all so much simpler. You don't have travel time. You don't have a lengthy recovery.

Nat Vogt: I have been okayed for a cochlear implant but last October I had a minor stroke. I am talking to you Jerry. Dr. Olson said that at that time they don't want to do the anesthetic. I am deaf in one ear and wearing a hearing aid in the other. Also, I forget my hearing aid today, so I am using this machine and I have never heard so well!

(Ed.Note: The machine Nat refers to is the personal receiver for the room's induction loop which she was using with an earhook.)

It has really gotten to the point where I don't hear anything. It is such a pain. I haven't been back to see Olson as to whether the anesthetic will be OK. It has been a year since the stroke. Should I go back to Olson and see whether they reevaluate?

Dr. Sladen: Any time you have a surgery you have to be evaluated by an anesthesiologist. The surgery carries the same risks as other surgeries. You have to be fit enough. I encourage you to go back and revisit with Dr. Olson about this.

Nicole: They are very concerned for your safety and that is a priority. I know someone who is in the process right now of getting a cochlear implant and they have to get a pace maker first. They review everything and make sure that before you have the surgery you have covered all safety concerns. You would not be moving forward if Dr. Olson didn't think it was a good idea.

Jerry: When I had my implant, I had a 30 day dry spell with nothing. Joanne had six weeks of this. Other clinics had a 2-3 week term. I don't get it, why such a vast difference in the amount of time between surgery and activation between clinics.

Nicole: I can speak to that. I cover quite a few clinics. I have seen people wait three weeks and others wait one week. It is based on how the clinic wants to run the protocol. After you undergo the surgery you need time to heal. There is swelling that occurs at the site of the surgery. Because we are using a magnet to attach the external processor on the head the swelling needs to go down. You need to make sure that you are feeling good and ready. That can change if something happens during that period.

We are typically seeing around 2-3 weeks now. That has also changed so much over time as techniques get better and better. We are not waiting 30 days like we were a while ago. Now it is generally about 2 weeks.

For one example, when someone from Alaska was flying to Seattle for the surgery they would actually be activated in a matter of days because they needed to go home. That was a really small time period and that was based on access to the clinic and making sure that they had everything before they went home. It really is the surgeon making sure that everything looks good at the site and the clinic's protocol.

Joan Baker: I want to address your comment about the different clinics. Every clinic is different, and every surgeon is different. I researched every surgeon and every clinic. I wanted to know how many procedures they had performed. The more they had done, the less complications were probable.

My Medicare insurance also helped me decide. I had to go to Virginia Mason. Mine was the least invasive. It is a little hole behind my ear and a tiny little scar. I didn't even have my hair shaved. It took me 7 days to heal. Not every doctor is going to be like that. I was deaf in my right ear for 45 years. Claydene, when she was with Bert, well my husband was there, and I cried! I had to focus on the activation and the sounds I was hearing.

After activation it was high pitched squeaky. Everything sounded that way. On the way home from Seattle my husband voiced all the signs on the road. By the time I got home I understood almost everything he said. The next few months were listening to birds and identifying sounds. It is a miracle every day.

When the world gets to me, I turn it off and go deaf. Then I hear my tinnitus instead. Every clinic is different, every surgeon, every procedure. Everyone's hearing is different. Your bodies are different. You have to rely on the expertise of that clinical team to evaluate you and be confident in what they do.

Nicole: I would like to second that a bit. We live in a place where you have lots of access. There is not just one clinic or surgeon who is available. There are quite a few. If you aren't clicking with an audiologist or need a different surgeon there are many options. Each surgeon also has different people that they have worked on with varying degrees of issues. Blood thinners, diabetes, etc.

I know some surgeons have age limits because they are not comfortable operating on people who are at a certain age. Nonetheless, there is no age limit for cochlear implants. Dr. Doug Bacchus in Edmonds had a patient who was 96.

Nicole: I want to start with Dr. Sladen and what happens the few months after activation and what improvements he usually sees in patients like the Daffy Duck or the tinny sounds.

Dr. Sladen: Let's stick with adult cochlear implementation. The electrode array puts off

current and stimulates the auditory fibers. We have a brain that knew what hearing was, so even though it is a rough system the brain is able to fill in the gaps. Our brains are remarkably plastic. It is different from normal hearing, but it takes information and interprets it.

People call the sounds foreign or robotic or mechanical, but after a few months it shifts and sounds more natural. That is because of the plasticity of the brain.

Device activity happens and then shortly after we have a programming visit. The levels we set shift wildly within the first couple of weeks. To get accurate hearing we need a good program. We want to get those levels stable. We also want to build up the person's hearing over the first few months. We might start softly and then make it louder and louder as the person becomes comfortable with it.

The typical visits are activation, a week later, a month later, three months later, six months later and then a year later. So, after a year we have seen a patient six times. After that first year, we see them every 1-2 years.

The research here is solid. We see significant improvements after six months and then a plateau. The majority of improvement happens in the first six months.

Nicole: We call exercises oral rehabilitation. That can help with comprehension and understanding. What do those exercises entail for you?

Jerry Finkbonner: In order to get away from the Daffy Duck sound I found a program online called Angel Sounds. You can use an iPhone or computer to hear words. It is online. They give you vocabulary words every day and then paragraphs where those words are used and then they will read it to you. You can follow along on the screen so that you see the words and hear the words to train your brain again so that you can recognize those words when you don't see them.

It is a matter of training your brain. It is a marvelous part of your body. Without it we don't function at all! But if it doesn't get exercise, as far as hearing things, it forgets about them. This is reteaching the left side, the one with the cochlear implant, to recognize sounds.

With Angel Sounds you get vocabulary and paragraphs and then you get choices for four different environments you will hear in and they give you a word and you need to choose it on the screen.

You can start with two words where you have a 50/50 chance, then four words, then you go up to six choices. This can be a challenge. You are basically reteaching your brain to recognize words.

I have a head set I purchased, and my son connected it to the television. As I watched the news in the beginning, everyone sounded the same. As time went along I distinguished between male and female voices. Then recognizing specific anchor people and reporters. When I left the television screen in the beginning I couldn't understand who was talking or who it might be.

Now I can be in the other room and listen to the television and know who is talking! My brain has now distinguished between individual voices. It has been a process. I have spent a year listening to angel sounds and forcing myself to listen harder.

Nicole: Claydene, how have you participated in exercises or rehab as a spouse?

Claydene Lederer: Not always positively but we had good support from grandchildren and when Bert was first rehabbing he got exercises for Tina Worman at UW medical center. We would sit at the dining room table and Mark would cover his mouth and read the exercises to Bert so that he was forced not we rely on lip reading but to actually hear.

A couple of funny things happened along the way. One day grandson Mathew came over and Bert was especially grumpy that day. Mathew said to me, "Wow, he is a grump today" and Bert turned around and said "I heard that!" We learned quickly that we couldn't talk behind his back.

Nicole: Panel, other than exercises or Angel Sounds, what other tools have helped you or can help you improve your hearing?

Joanne Boschman: Well I have the same feelings as Jerry. I have gone to the Cochlear Family website. They send emails too. They have many lessons and my husband printed them all so we have a huge stack of them. About six months of these. He does them with me three times a week. It is really fun.

I have a session every Monday with professionals. They cover their mouths. My biggest thing was to learn to listen with my ears instead of my mouth. For years I have done nothing but speech read. It was a real chore for me. But there is something else I have done besides that. I turn on the television to Erin Burnett, not because of the programming, but the people! I am able to listen without captioning. There is an odd person I can't hear, but in general I can hear everything they are saying.

I went ahead and watched sports. With hockey commentators speak quickly and you don't see them. With baseball that was a whole new thing. I couldn't hear them at first but gradually I heard a few words and then I heard whole sentences. There was no one on screen for me to lip read. I always needed the person up there. Those things really helped between the television with no captioning.

Nicole: That is pretty advanced. Audiobooks might be a slower approach.

Claydene Lederer: Hearing loss can be isolating. After a couple of years, we realized we could actually go to a show that wasn't captioned. Garrison Keeler was here in Bellingham a while back. I bought tickets and took Bert and I was worried it wasn't going to work. Normally going to a function like that with a hearing loss person they will ask what was just said, I tell them and I miss the next line. It was frustrating with those situations.

Keeler was telling a joke a minute and I realized that Bert was laughing at the appropriate times and not asking me what was being said!

Jerry Finkbonner: As far as socializing it can be difficult, but you have to put yourself out there and stretch your hearing abilities. Regal Theaters captions and you can utilize it. Go back to the movies if you haven't been! Mt. Baker theater, with more things being looped now, it is much easier to understand. Don't think that you need to isolate yourself. There are many things you can do. With cochlear you have all kinds of devices to utilize.

You can use your iPhone. There are mini mics you can wear or put in front of you. There are more complicated program devices and portable program devices. There are lots of things that help your being successful. I just started a class at WWU for people with CIs and it is wonderful because there are interns that meet with you for an hour each week. They talk about devices and environments and how to deal with them. It is more one on one, it is not a class of 20-30 students. It is an outstanding opportunity.

Dr. Sladen: My favorite training is speech tracking. This is what you are describing. You listen and read at the same time. The reason I like it is because our reading is based on our knowledge of sound. It is the adage, "You can sound it out." If you read, "The boy ran down the road" you sound them in your head. If you have just been implanted, you can use these to boost your skills.

You can also get books from Amazon that have an audio connected to them. You can read and hear the book at the same time. I download these to a Kindle and then I hear and see it simultaneously. This is different than a regular audiobook. This is words and sound together. Whisper Sync Ready.

Speaker: As far as music is concerned, are you hearing music the way it should sound?

Nicole: That question is very individualized, and each person will hear differently. There are exercises like we are talking about that are specific to improving music appreciation.

Jerry: I had music going constantly. The Mormon Tabernacle Choir initially sounded like

screaming brats! But in a couple months it sounded wonderful! It is training. I think that you should have music as part of your curriculum of learning and adjusting.

Mike: We need to wrap up. The enthusiasm is great. Thank you all so much. Have a great weekend and thank you to the panel.

[Applause]

[End of meeting]