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Cochlear Implant Panel

Nancy Hammons

In the last nine years I've been doing cochlear implant seminars and workshops. For this particular workshop, what I want to do is ask for volunteers from the audience. I have 5 chairs here and I would like to invite five of you to come up and share your experiences with us.

Most of you have heard me talk about my cochlear implant. So I want to give others an opportunity to share their experiences--both emotional and spiritual. I found that, following my implantation, I was on an emotional roller coaster. I was not expecting to have such high highs, and deep valleys of exhaustion. As a result, I became curious as to how other people felt about these issues. And as time went on I came to realize that many different factors must be weighed when considering an implant. So we need to hear from many different people.

Carl: My name is Carl. I was raised in Illinois. I was diagnosed at the age of two with a profound hearing loss of 95 and 100 decibels. I was fitted with a body aid and then hearing aids. I went through regular school with a special program that was available in homeroom. They were there to help me if I needed help with anything in the classroom. I was implanted at University of Miami February 14, 2001, and activated on March 9th, 2001. So it has been 19 months.

Lori: My name is Lori, and I'm from New York City. I've had my implant for a little more than six years, and I was deaf about 7 years before I was implanted. I only wore one hearing aid. I went from normal hearing to profound hearing loss very quickly.

Eza: My name is Eza. I was born and raised in New York and I live now in Florida. I had my implant four years ago. I like it very much; it is a whole new world. I never heard anything before as I was born with no hearing.

Linda: My name is Linda and I live in Cincinnati, but my accent is from Texas, where I was born and raised. I lost my hearing eight years ago. I was implanted almost two years ago. It changed my life and it has been an absolute miracle.

Carol: My name is Carol, and I'm now living in Florida, in Coral Springs. Before that I had spent most of my life in New Jersey. I've been deaf for six years now. That was hard for me to say because I have never really thought of myself as being deaf. I had a gradual hearing loss, and all of a sudden one day it just disappeared completely. And I was completely devastated. I went up in an airplane to go to my father's funeral, and when we landed I had no hearing. It was a devastating thing. I made a decision to get the CI last year, and was implanted. My life began then.

Barbara: I'm Barbara and I live in Ohio, up near Cleveland. I had my implant in April of 2001. I was born hearing, maintained my hearing, until maybe about 14 or 15 years ago. I read lips very well and because of that, I was turned down the first time I was evaluated for an implant because the doctor said I did so well with lip reading I did not need it. The second time I was approved and I love it.

Karen: My name is Karen and I'm from Boston. I was born with a serious hearing loss and I've worn a hearing aid in my right ear all my life. At the age of 37 I developed a virus and I couldn't hear in my good ear. I had lost most of my hearing and went from an 85-decibel loss to 110 overnight. Then I developed tinnitus, which was a new sensation for me. For the next six years, I debated whether or not to go for a cochlear implant. I thought I could try living this way. But I have 3 children, and I'm used to hearing their voices as well as my husband's, and being able to respond to them. So I decided last June of 2001, that I had had enough and I went ahead with the implant at New England Medical Center in Boston. I remember vividly how my tinnitus was wild before the surgery and afterwards gone. Many people told me, watch out, it's not going to sound like what you remember. Okay, fine, and when they turned it on, I was very disappointed. But the doctor told me to keep wearing it, and that it will get better. I had a lot of encouragement. So I continued to wear it and sure enough it has been almost a year since my activation, and I am really happy with it.

Nancy Hammons: I want to ask you all—: was it the fear factor that prevented you from having an implant sooner?

Response: It was the fact that it involved surgery. I never had surgery. I never wanted surgery. I'm a guy. I'm very athletic but I was terrified of surgery.

Response: This may sound odd, but I was afraid that it wouldn't work, and that it might be better to just hope that it will work some day, rather than find out now that it doesn't. I was really afraid that this was my last chance of being able to hear again. It really scared me to think that it might not work and I would have no other chance.

Response: I wasn't frightened of the surgery at all. It was fine.

Response: Like Lori, I was afraid that it would not work and I had had several surgeries that were extremely painful. All I could think about was the pain of the recuperation period that I went through with those surgeries. But ultimately the big fear was my fear that it would not work. My daughter asked me what I had to lose and pointed out I had everything to gain. After she said that, I realized that she was right. What have I got to lose? I never looked back.

Response: I never really had fear of pain because I've had a lot of surgeries before and was never bothered that much by pain. With this surgery, they gave me a shot right after the surgery and after that I took some Tylenol and that was it. I never really had any pain. I did have two fears: One, that I would lose my residual hearing. How much hearing was that? I could not understand a word that anyone said. I could hear a little sound with one ear with a very powerful hearing aid.

But that was it. So I made the choice to implant the ear that I heard really nothing with a hearing aid. That way I had nothing to lose as far as residual hearing was concerned. I was also afraid of the surgery, but this was the easiest surgery I ever had. Not only that, but also every other surgery I had before this, something was taken away from me. This one gave me something. Something wonderful.

Response: When the doctor told me I did not have to do it because I read lips too well I was relieved because I did have fear of the surgery. But then I had a good friend that I had met on-line that was profoundly deaf, and she had the implant. She did very well so that encouraged me. That's when I started thinking about it again. The scary part was that it was after a lot of surgery, and I had had enough surgery and wanted no more. Then when I read the medical release form before the surgery, I realized that despite the list of things that could go wrong, none of them had happened to those I knew who were implanted. I had a very interesting experience in recovery. For some reason or other, I couldn't get my eyes open. So when I can't hear I'm more apt to sign to someone--whether they know signing or not. So I was in pain. I wanted coffee because I hadn't had any, and so my eyes were closed, and I kept trying to sign to the nurses that I was in pain and I wanted coffee, I wanted water. They are trying to take my vitals in one arm and I'm signing. I, of course, could not hear a thing they were saying. Finally they went to find my daughter and got her to come and interpret.

Response: There is a fear of the unknown. I had fear of surgery, too. I remember the morning I arrived at the hospital, I was so nervous. Also, like the others, I did have fear that it would not work.

Nancy Hammons: I have a question for you personally. I had my implant done nine years ago, and the worst thing for me was that they shaved my head and gave me a mohawk. That was the worst thing. What was your worst incident?

Response: All I had was a headache. They didn't shave my head. They shaved my head a little bit but not very much. I had a bad taste on my tongue for about a couple of months, but it wore off. But waiting to be activated was the hardest part, because I couldn't wait to be activated to find out what a cochlear implant is all about.

Response: If I had been given a mohawk, I would have been very upset. I asked my surgeon how much hair he was going to shave, and he showed me exactly. This was a long time ago, so people did shave off more back then but he left enough to cover up the surgical area. I had no pain. I didn't even have prescription pain medication. I had no taste thing, no balance problems. The month wait for hook up was the hardest.

Response: My surgery wasn't too bad. My hair was shaved but not a large area. One thing that bothered me was that I had to go home with a bandage around my head and I did not go out of the house for a couple of days. I went back to the doctor to get the bandage off my head and then I could not wait to get my hair washed. It felt so good.

Response: The stitches were itchy but otherwise, everything was fine. I had my implant four years ago, and I had my taste back after maybe three months.

Response: I too was concerned about was how much of my hair they were going to shave. My doctor said, "You women drive me crazy. I'm doing microsurgery. I'm opening up your head,

and all you can worry about is how much hair you are going to lose.” I said, “It's a woman thing.” I went home after 24 hours. The biggest side effect I had was that for 24 hours, maybe 36 hours after surgery, I developed numbness on half of my tongue. The only way I know how to describe it is that it was very similar to what happens at the dentist office when you have Novocain. It also affected my taste buds and being able to know hot from cold. I am a coffee drinker and so I had to be careful about coffee. My doctor said this is one of the possible side effects because of the close proximity of the operative site to the facial nerves. I will tell you that it was a very small price to pay for being able to hear. I had been afraid of pain, but they gave me a shot, as well as pain medications to take home with me--Tylenol 3, and I took that pain medication for about a week. So the pain was nowhere near as intense as I had expected it to be. It was really quite manageable. The numbness of my tongue, and the taste, gradually cleared up after about a year.

Response: I, too, asked my surgeon how much hair he would remove. And he did not take much at all. My biggest aggravation was that no matter how much I tried with as many mirrors as I could, I cannot to this day find where the incision is because it is so small. As far as the side effects, I did have some taste impairment. Things tasted salty to me, which I thought was unusual and I had never heard of that before. That disappeared and then it turned metallic, and eventually also disappeared. The biggest side effect that I had was due to the fact that I am allergic to Bacitracin and they used that on the incision. So I got an allergic reaction on my skin—redness and so forth. There were no other side effects. I never took more than regular Tylenol for pain.

Response: The worst part was the ride home. I had my surgery done about 60 miles from where I live. I had to stay a long time. There were some problems, and my daughter drove me home at night. I couldn't rest my head back on the seat. I was so tired, and she kept saying, “I'm sorry, mom,” because every little bump in the road was so painful. I also had the taste problem but that wasn't too much of a big deal--some things tasted like cardboard. The other thing was that I was so dizzy for about the first week that I had difficulty getting up to go to the bathroom, and I had a lot of stairs to do at home. So I would go up and down the stairs on my fanny or on my hands and knees.

Response: The worst thing after surgery was the metallic taste in my mouth and the doctor and nurse said it was from the anesthesia. That lasted a few days. Getting back to the fear, I was afraid to have my whole side of the head shaved off—but as it turned out he shaved very little. I have a very high tolerance toward pain. So I only had a few days of painkillers, about 3 or 4 days and after that I was fine.

Nancy Hammonds: This is a guy question. The question is why do men have such a hard time with implants and talking about implants? Women tend to talk of their experiences more and share them with others.

Carl: I never really thought it was hard. I don't know how to answer that question. All I can tell you is that it wasn't hard for me. I have this desire to hear. When I got my implant, it was a little annoying because I never heard these sounds before. It took me six months to get over that annoying stage, and after six months I was doing very well with the cochlear implant. I was constantly improving from that time.

Response: After communicating with hundreds of implantees I have to say that men treat this entirely differently than women do. Women tend to communicate more and will tell you what they are worried about, what they're feeling, what it's like to go through the surgery. With the

men, you usually get very technical questions. Once in a while you will get a man who actually admits to being concerned. They're not going to say they are afraid of the surgery and what you usually get are very cut and dried questions from them.

Response: I want to go back to what was the very worst thing after surgery. The absolute worst thing was the day after surgery when my doctor was checking my stitches, and he showed me a photograph of my head cut open with the implant and the wires that hold it into place. That was the absolute worst because I'm not a medical professional, and looking at my scalp open with the bone and implant, it was pretty shocking.

Nancy Hammons: Here is the rest of the male question. As a man, do you feel self-conscious about having an implant showing with your short hair, or do you try to cover it up with your hair?

Response: I have a lot of confidence in myself since I got my cochlear implant. I feel less stressed. It really changed my life. It was something that I wanted to do and I just went along with it. And I feel like I'm a better person now. Before I got my cochlear implant I would never get up here and talk about it because I was so concerned about what if I couldn't hear the person in the audience. Now I can hear them. So I'm not afraid any more.

Nancy Hammons: The next question is, how much time off work is involved in a cochlear implantation? This is including pre- and post-operative time.

Response: I am in construction and I was back at work in two weeks. I was able to do anything after two to three days. I could walk around and watch TV. The whole point after surgery was to relax as much as I could.

Response: My surgery was Wednesday morning. I was required to stay overnight. I really almost took the subway home the next day because I felt fine and I did not have a bandage on my head. Friday I had my nails done. Sunday I took the bus and a train to my parents' house and came back. Monday I went back to work. I was a little bit tired the week following my surgery. I had told them at work that I might take the following week off but I just didn't need it.

Response: I had my surgery on a Wednesday and I think I went back to work on Tuesday, after they took off the bandage. I didn't want people to see me with that, as it was big. I went back to work and I was concerned about my hearing because, but I did OK with a hearing aid in one ear.

Response: I had my surgery on a Tuesday. They kept me 24 hours and I think I left the hospital Wednesday afternoon. The doctor's orders were to take it very easy for a couple of days and to avoid stairs. Some people experience a balance problem. So I stayed upstairs for about two days, and watched TV, and enjoyed being waited on, enjoyed my meals brought to me by my family, and just generally took it easy. By the following week, Monday, Tuesday, I was feeling fine.

Response: I stayed out for as long as I could manage, because I don't react well to anesthesia. It seems to stay in me for a long time. I've always had that. I just take it easy for a while and then I am fine.

Response: I didn't take any time off before the implantation. But since I work

with animals, I was not allowed to go back to work for about four weeks. It was mainly because of the proximity to the animals, being around the dust and things like that. I wasn't allowed to drive for a week because I was too dizzy to walk. That was about all.

Response: I'm a homemaker. I stay at home and take care of my children. So I didn't have to take any time off from work, but my husband took time off from work. I had my surgery on Thursday and came home Friday. He was home on Friday to take care of the kids and get them home from school. Friday he came and picked me up from the hospital and brought me home and stayed home on Saturday. That was great. Friends helped with the cooking for 3 nights until I was able to take over. I experienced dizziness for about two weeks. I found that the best thing to do is to take it slowly. I was walking to school to pick up my kids. I realized I was running late and my heart began to race and I experienced very bad dizziness. There was a street pole that I was able to grab and regain my balance. I thought the other parents would think I was drinking at home and I was drunk.

Nancy Hammonds: Were you able to choose the ear you had implanted, and was there any discussion about this with your audiologist or physician?

Response: They asked me which ear I wanted implanted. I wore two hearing aids. For some reason I always thought I heard better with my right ear, even though both of my ears had the same hearing loss. In the past, implants have been done on the worse ear. Nowadays they recommend using the better ear—I guess because, and I'm quoting studies, people who have done it on the better ear seem to get better results. Now, that doesn't mean that it doesn't work on the worst ear. It just means it might not take you as long time to adjust with the cochlear implant on your better ear. They couldn't make that decision for me. They told me it is up to me. I was went with my heart and feelings and I believe that was the right thing to do and I did it. I'm glad I did my better ear.

Response: Back when I was implanted, things were very different. This was six years ago. They routinely implanted your worse ear unless your ear had not had hearing in a really long time and your other ear had. So I had my slightly worse ear implanted. You have to consider, too, your hearing history. If the worse ear has never had any hearing, that could make a difference. Each case is different and you have to talk to your audiologist and surgeon.

Response: The asked me which ear I wanted to have done. I chose my left because I am a lefty and do a lot of things with my left hand.

Response: The audiologist and I talked about this. They recommended that I have the worse ear done. Both of my ears were extremely bad. To me it made no difference. However, since I've had my implant surgery, I wish that I had considered the thought of having my right ear done, because I do a lot of the driving in my car. So if you have a passenger that you are trying to listen to, then had the implant been on my right side, it would have made listening a lot easier, whereas now with the implant on my left side, I use my microphone attachment for my implant to enable me to hear more clearly. If I had to do it over again I would choose differently.

Response: I'm a righty and I had my left ear implanted because I wasn't giving up that little bit of residual hearing. My doctor said it really didn't matter because my testing was the same. But even though the testing was very close with both ears, with my left ear I could hear nothing with a very

strong hearing aid. But I could hear somewhat with my right ear with a very strong hearing aid. So knowing myself, I chose to have my worst ear implanted, and I'm not sorry about that.

Response: Actually, I feel pretty much the same way. They did ask me what I thought as far as which ear, and I said that I would prefer they use the one that I felt I could not hear at all with.

Response: My left ear is completely deaf. I cannot use a hearing aid on that side and I never wore a hearing aid on that side. However, my right ear had 85-decibel loss in the beginning and fluctuated for six years up and down. That ear wasn't great but it was serviceable because I had a hearing aid in that ear. When it was time to make a decision about which ear to implant the doctor gave me that choice. We both agreed that we should do it in the right ear. We weren't sure it would work in my left ear. I'm happy with the choice

Nancy Hammonds: What I'm going to do now is read off some of the questions and ask you to choose which one you want to answer. The questions are: The brand of an implant, how important was that for you to choose? Second question: How does a cochlear implant compare to the sound of a hearing aid as far as distorted sounds, clarity and distance? Does anyone on the panel have a problem with the device or do you know someone who has had a problem with the device? Third question, are you happy with your audiologist? Is the audiologist aggressive enough in mapping for you? Mapping means programming of the cochlear implant. Did you adjust to the device slowly, such as wearing it in the evening, on the weekends, or did you have to wear it all the time? Last question: what one last thing would you like to share with the possible CI candidate?

Response: I know the number one problem with the device is moisture. The good news about it is the manufacturers are coming out with a waterproof sleeve that you can slip on. It is like a mini sock. You just put a damper in the sock and it prevents moisture, and it works great.

Nancy Hammonds: That is wonderful to know. I have had had my implant for nine years, but for some reason in the last month-and-a-half I dropped my implant in the toilet. I totally freaked out. Fortunately, I was able to take it apart and put it in the window, and it's fine. So there is hope for some of us who get our implants wet.

Response: Here is what I would tell a CI candidate. In a nutshell, I know it's very scary. But a lot of people have done it before you and you can do, too. You have to want it for yourself, not for someone else. There is a lot of support out there for you. And no matter how scared I was, I cannot imagine where I would be today if I didn't have my implant.

Response: The question is how do implants compare with hearing aids, distorting sound and distance. I used to wear aids in both ears. After having the implant, I got hooked up and I only wear the device. The sound is very different. With the hearing aids I never really heard everything. Now I can hear the dog barking outside, which I never could before. I couldn't believe it—everything makes noise. It is a whole new world. With the hearing aid I missed all of that and I would not want to go back to that again.

Response: I think people have to decide what's important to them. You have to decide if your life will be better if I can hear again—or are you comfortable as you are? I can't answer that question for you. I lost my hearing eight years ago. Then two years ago I had my implant because I felt so left out. I felt so isolated. I was so depressed because everything I knew, every person I knew, every social structure I had ever existed in, was in the hearing world. You have to answer

for these things for yourself. What finally pushed me over the edge and helped me make the decision is that my daughter was leaving for college and I could not bear the thought of not being able to communicate with her. Like Nancy said, I felt like a bird released from a cage, and I have never looked back. My life was given back to me.

The question of brands has never impressed me. The one important thing to me was choosing a brand. I was given a choice of any of the three. I chose the Nucleus. The reason that I did was some years before I had to have an emergency MRI. It was a very scary thing. They thought I had a brain tumor. God forbid I should ever have to have that again, but if I do I want to be able to do so. I don't want to have to worry about what's going to happen to my implant. That's really the reason I chose this, because if I need something like that I want to be able to have them take this magnet out of me so I can have done what needs to be done. Then they can put it back in and I will be able to hear again.

Response: I think the most important thing is to follow through. Don't give up. You will get depressed. But listen to something every day in your house. Keep the TV or the radio on. My first very distinct thing I'll never forget was the temperature on the radio. I got so excited.

Response: The sound quality between a CI and the hearing aid is very, very different. I had a very good audiologist who helped me with the mapping. He let me take the driver's seat on the equipment, showed me what button to hit and so forth. That helped because it allowed me to be in control. And he also advised that I wear it as much as possible because the brain is working like a baby's brain. A baby hears all these sounds but don't know what it is. And we need to retrain our brains.

Nancy Hammons, Region 4 Director- Western States to Australia. Progressive hearing loss starting in early 20's Late deafened at 40. Cochlear Implant user since 1993 Nucleus 22, has been an active member of ALDA National since 1993 Toronto Convention stole my heart and made me part of a wonderful ALDAN family.

Even with 7 generations of various kind of deafness in the family, I wasn't prepared to lose my hearing during childbirth. I'm employed by Deaf Counseling, Advocacy and Referral Agency since 1989 as a hearing loss counselor/caseworker in Beautiful S.F. East Bay Area. After 8 years of denial and hibernation I found DCARA first then ALDA.

My life has been a series of wonderful events and roller coasters. Awarded as "DCARA's Employee of the year 2002" Board member of Hearing Impaired Publications (hearing loss magazine for HOH children), Northern California Center of Law Board Member and a National Consultant on "Diversity on Hearing Loss and Cochlear Implants. It been my pleasure to give back to others in the area of HOH and Deafened Services.

This publication is available to the public in this on-line format. If you are interested in using any portion of this publication the reference is as follows:

Hammons, N. (2003). Cochlear Implant Panel. In L. Piper & D. Watson (Eds.), *Selected proceedings of 2002 conference of the Association of Late-Deafened Adults*. [on-line] available: <http://www.alda.org/aldapubs.htm> and <http://www.uark.edu/deafrtc/publications.html>