

Rough Edited Copy

Cochlear Americas  
CA-CAN Chapter Meeting  
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>> Good morning.

We are a smaller group today so we have time to talk and answer questions people may have.

The first thing I want to do is Laurel Olson who is the audiologist with cochlear usually comes to the muting, but, she had her baby on Wednesday.

She had a baby boy. Named him Omar. He was a big baby and Laurel is tiny.

We will wait until the newcomers sit.

I don't know how many have heard, next weekend there will be a gathering at the zoo for people with cochlear implants to meet other people that have them or are thinking about it.

If you have not seen it information you should take a look at it if you are interested. It is free?

>> Is it inside the zoo.

>>SPEAKER: It says Cincinnati zoo. I think it may be inside somewhere.

>> If you go on the website it will have a map and show where it is.

>>SPEAKER: We will go around and say who we are and if we have an implant or if we are here for information. We will answer the questions after Mary Jo presents. First we want to give a feel so everyone knows who everyone is.

I am Sister June. I have two implants. I have N six and this one I hope to have activated.

>> I am Mary Jo and I have two implants. The first one I got in June of 2013. A little over two years.

The other one I just got this past December and it is a hybrid. The other isn't.

They are both N six.

>> I am June Rieter. I have two implants. I just got this 16 weeks ago. We will wait until I get used to this one before I upgrade and get used to a new one.

>> I am Jane Hoffman and I have two implants.

>> I am Don Hoffman Jane's husband giving support where needed.

>> I am Karen, I have one cochlear implant on the right side and hearing aid on the left side. I am thinking billion having another one on the left side.

>> I am Brian and have one implant in 09 and deaf in other ear. I am waiting to see.

>> I am scheduled for surgery on December 6th. I am scared. I am not sure about it. I have two hearing aids now.

>> I am Bruce and here to support my wife.

>> I am Michelle and my mom is scheduled to have implant on November 18th, she is close to your date for the first time.

>> Did you hear her?

>> Yes. November 18th right.

>> Yeah.

>> I am Yvonne, Michelle's daughter and scheduled to have surgery November 18th. I am very apprehensive about the whole process.

>> I am Becky and activated two months ago. I am 100% delighted with my results. Beyond my imagination even after hearing you talk about how great it is. Like Karen I am thinking about the side with the hearing aid implanted also down the road.

>> I am Jean to support her.

>> I am Dale, I have implant on right side six months ago. I am still learning.

Not perfect yet. I am continuing to use hearing aid on the left. I don't know if it

is confusing my brain having electronic and acoustic sound but I think I need it. I am getting by with it. I understand most of what you say but not all of it.

>> I am Sister Marie Clemmons and I have a hybrid I got in 2011 when it was experimental. It was approved in early this year and when it was improved I was upgraded to the N six.

>> My name is Caprice and I am just a driver. He is interested in what you are all doing.

>> Apprehension is a good word. It is hard to convince yourself to go with it. I am pretty close to having to. My hearing is not good at all. I need the help. Has technology improved recently in the last year maybe?

>> It has.

>> So there is something to look forward to.

>> We can talk about that a little later.

I have asked Mary Jo, we had a speech and hearing center that had quarterly meetings and they would have someone tell their story. To get the conversation going I asked Mary Jo to tell her story. You want to come up here.

>> Sure.

Mary Jo:

>> I have to have my remote. I play with it loose. I am sure some of you do too.

My story, I am sure that what I say will resonate with a lot of you. There will be things in my story that you have experienced or have thought about or had happen to you. But, I think the more you hear of other stories and see how similar they are to you, I think that helps. First of all you know you are not going crazy. But, secondly, you can talk with those people because they have actually shared your experience and they can tell you perhaps how they handled

something. I hope the things in my story will be helpful for someone out there. I started to lose my hearing in my 50's. Which is kind of early, they tell me for age related hearing loss.

In the beginning, I realized I was having trouble on the telephone talking with a client and problems in meetings, I would miss important things that people had said.

So, I had pollen allergies all my life, so when I was struggling with hearing I would go to doctor and it was ear wax or my Eustachian tubes were clogged and they would say do this and you will be fine.

I went to an ENT and expected that kind of answer. But it wasn't what I got.

I can still remember the shock and the despair that I felt when the ENT said you have hearing loss. It is going to continue to get worse and I remember him saying, you will never be deaf. There will always be some sounds you will be able to hear. How do you cope with that? He said the one ear was bad enough that I should consider a hearing aid, at least in that ear.

So that is what I did. I finally got my first hearing aid in 2001 and not long after the other ear because that went quickly.

I remember getting the first hearing aid and went into the office and I worked downtown and it was a windy day. The sound of the wind was so loud and it took me a while to identify what it was. I thought oh, my gosh, how am I going to adjust to the sound of the wind in the hearing aids.

The hearing aids help somewhat, but, since my major problem was not being able to understand speech, hearing aids can only help so much with that. I used to ride the bus to and from work. With hearing aids, you cannot carry on a conversation on the bus. All you hear is the engine. I would get so frustrated

sitting with my friends that I was always able to carry on a conversation with and I couldn't do that anymore.

The frustration, the -- you begin to feel isolated when you can't hear, right?

Just riding in a car. If I had passengers I would tell them I can't carry on a conversation and drive at the same time. I don't know what you are saying if I can't look at you in the face.

I would tell them right away. No conversation until we get to where we are going.

If I was a passenger in the car I would strain my neck trying to read someone's lips and if you are on a long drive that gets very uncomfortable very quickly.

Directional hearing. You don't have with hearing aids. I would be driving and because I guess because I complained about the conversation on the bus and the noise from the engine I think the audiologist put in some compression. So when I was driving I didn't always hear siren as soon as I should have. When I did finally hear it, until I could get a visual on that -- whatever kind of vehicle it was. I had no idea where the sound was coming from. It could be in back of me, down the street on the right side. This used to really worry me. I would have to constantly remind myself to listen and look. If everyone else is stopping, there is a reason. Pull over and stop with everyone else.

But, that is a dangerous situation. But you have to find ways to deal with that if you just have hearing aids.

The frustration that I kept feeling and the isolation, the worse -- as my hearing continued to worsen the isolation and avoidance of activities became worse. As most everyone understand now, isolation also brings depression. I was really struggling with just feeling no need to go out anywhere because I couldn't

understand what people were saying anyway so why go?

Each time I got a new hearing aid I would be so hopeful that this time it was really going to help me understand speech. They did for a short time in the beginning and as my hearing worsen they would no longer give me that ability.

Every time I went in for my hearing check, it would have -- my hearing had gone down.

Finally, I can remember the day when I went in to UC for my hearing test and the audiologist I worked with, Stephanie Lockhart did the hearing test and said I can't help you anymore with hearing aids. Have you thought about cochlear implant? I thought what in the world is that. I had no idea what a cochlear implant was.

I went home and googled cochlear implant. I read everything that I could. She set up the testing appointments to verify I was a candidate and set up the initial appointment with Dr. Samy.

After that of course, I was a candidate and I talked to Dr. Samy about it and went home and had all the literature and ads from the three different implant places and I am trying to make a decision.

One thing that really helped me and those of you who are concerned about upcoming surgery on trying to make a decision. What it is really like and what is everyone's experience. There is a woman named Arlene Romof. This is her second. Her first was written in 1997 and it is called hear again, back to life with a cochlear implant.

Like I said it was written in 1997 when she got her first one. She was deaf in both ears but got one implant.

This one is a lot more recent and her internal implant failed. Since she was deaf in both ears when the one implant failed she was totally deaf again.

It talks about her problems during -- when she had no hearing and how it was when she got the first one and had some hearing. It talks about her decision to get a second implant.

She writes her books in an interesting way. It is like a diary. Every day there is an entry and she talks about improvements and problems and maybe disappointments or hopes.

They are both good books. This is the most recent. I will lay it over on the table or pass it around so you can look at it. It was very very helpful for me because it gave me an idea of what one person's surgery experience was. What her healing was like. Of course it is different for each of us, but, it kind of gives you a feel for what you can maybe expect and look forward to.

It wasn't a totally difficult decision for me to make to have the implant. More than anything in the world I wanted to hear. I wanted to be part of things again. I wanted to be part of my family again. I wanted to take part in things.

Obviously, hearing aids had not done that for me. My mantra became, what do I have to lose. I knew my hearing was going to continue to worsen, that was a given.

I knew there was little hope with my hearing aid. I have had had 14 years of hearing aids. I could see no hope there. So, all I could think of was I have nothing to lose. I am going to go at least there is a possibility. There's hope if I do the implant. I went ahead and scheduled it and the first surgery I had dizziness for maybe a week. The second one I didn't have any at all. With the first one I had a great deal of pain for the first day or so. The second one I didn't have any.

So just with my surgeries it varied. You don't know until you do it. I had some



effect on my sense of taste. But that improved a great deal.

I just felt I was going to bite the bullet and do it. Afterwards, with just the one as I worked with it, and practiced I would get -- in the beginning I would get children's books, tapes and matching book. I started out that way. Then I went to the adult books and tapes and get the book along with the tape so I could follow and pick up the printed word what I missed. That helped a lot because your tendency when you don't understand things is to tune out. You may be with a group of people but you are not a part of the group. Because you can't understand so you kind of tune out and fake it. Yeah, sure, you know. You just go on with that. Your brain gets used to do that.

You have to work and wake your brain up again and you have to make it begin to listen.

I used the books on tape. I used angel sounds which is a free download on the computer.

I need to be working with that even -- I still need to be working with that.

Sometimes it is easy to get out of that habit. It does help. You have to realize, it is not just activated and suddenly your own hearing is back. It is not. When they activated my first one I said it sounded like Mickey Mouse or Donald Duck. Your brain adjusts to that and first thing you know it sounds like the speech you remember.

After I got my first one it was about a year or so later and I realized, hey, when I am talking to someone I am listening with this side. I noticed that I would sometimes kind of turn my head because I was listening with the implant and not bothering with my hearing aid anymore. I was working more on this side. Once I realized I made that switch. I decided it was time for the second one. I have

never been sorry that I did that.

You do begin to get your directional hearing back again when you have both.

Your brain is processing the same sounds out of both sides. You begin to get that directional hearing.

I can hear a siren much sooner than I could with my hearing aids. I am beginning again now to know where it is coming from. If you read the book, "listening closely". She talks about that. How her husband would have to tap her on the shoulder so she knew where he was speaking from. One day they were at a flea market and he shouted her name, Arlene and she turned to where he was. He just looked at her. She had not been able to do that for years.

Your brain is an amazing thing. It begins to remember and do the things the way it used to do when you had your hearing.

So, I have both implants and I would never go back.

(Applause)

If you have any questions, just shout them out.

>> Talk about the new technology.

>> The new wireless pieces are incredible. The TV streamer I have on my main TV downstairs and since my son and daughter-in-law moved in temporarily and live downstairs I have not been able to use it a lot.

I have a small TV upstairs and I have the mini mic and I connect it to the audio jack on the TV upstairs and it sends the sound from the TV right to the processors. That is one of the way I practice now. Every day I turn on the 4 o'clock news and anymore -- those captions with the news program are so far behind I don't look at that. That is good. It forces me to listen and understand the words that they are saying. I am doing better and better with it. Without the

little mic send it right to my processors it is a lot more difficult.

The other thing that I've started to use is the telephone wireless piece. You can clip it on or there is a little rope thing you can wear around your neck.

You pair it with your cell phone or MP3 player if you want to listen to music. You pair with it your cell phone and you get a call and you push a button and you can listen through your processors and talk with just that little thing around your neck.

I have not been able to talk to my daughter on the phone for years. Just yesterday, she sent me a text and said can I call you. I get the little thing all set up and turn it on. When she calls, she talks fast and tends to clip her words together. But I could understand most of what she said. To me, that is like someone giving me my life back. With these new wireless things are amazing. Just because they send everything to your processor and your processor is set up according to what you need.

>> How old when you when you got your first implant?

>> Let me think, 70. Yeah. I am 74 now.

>> I am 75 and just got my second one.

>> 86.

>> How old were you when you got your first one.

>> 87.

>> 79.

>> Personally, I don't think age matters. I don't think age is too much in the equation. I think the most important thing is how badly do you want to hear. How important is it to you? Are you willing work at it after you get it? It is not like it is turned on and suddenly your normal hearing is back.

A lot of people -- I was one, I could understand right away when they turned it

on. It sounded funny, but I could pretty much understand the words the first day after I got home with it. I went outside and my neighbor, a couple condos up and said hey, Mary Jo, can you hear me? I could. Some people it takes a little work before the understanding begins. But that is an individual thing. I think the main question is, how badly do you want to hear? How important is it to you and how much work are you willing to put in on it to make it work for you?

>> How many of you could hear or understand some speech when you were activated? Even if it sounded funny?

Who could not understand anything?

Most of us could. But now, how long have you been activated?

>> Two months.

>> How you hearing now?

>> Great. These people were the first two people, I was like I can understand them without looking at their mouths. I could understand as long as I was watching but if I turned away it was still too funny sounding. We were at lunch one day about a week later and I looked down to do something on my phone and I realized she said something while I was looking away that I totally understood. We got in her car and I was in the back seat sitting right behind her and she was talking and I realized, oh my gosh, again, I can understand what she is saying. It was a week later. It was beautiful.

>> That is what we call a wow moment.

>> Yeah. It is neat when you realize you taken a giant step forward with something. Wow moment is right.

>> With your wireless accessory for the phone, did someone help you set it up or were you able to set it up?

>> Actually it is in the book that comes with it. When I if I could up, Lisa Houston the audiologist set up some things. But sometimes they come unpaired for whatever reason and it is not that difficult to set them up again. There is a button you push on there and something you hit on the phone and they are paired again.

>> The first time the audiologist, if you bring the equipment with you she will pair it for you. We had a hard time pairing our TV streamer, we didn't have the right audio -- once someone found it it was simple.

>> Mine kept cutting out. Maybe I have it on the wrong jack.

>> By the wrong jack you mean you are plugging it into the wrong place?

>> On the TV. I thought we were putting it in the right thing but we were not. You need the audio input or output or whatever.

(Laughter)

>> If you need to try them both.

>> On my visit with Dr. Samy, Lisa Houston ask what three accessories I wanted.

I had no idea how to answer that. So I will probably go by what Becky has.

What do you have?

>> All three. TV streamer, mini mic and cell phone thing.

>> You need the remote, that is an accessory. You want the remote. You want the fancy one. The one with the most features on it so you can make your own adjustments.

>> I take this everywhere with me. Some people just set it on one thing and let it go. I don't do that, I change it according to where I am and what the situation is. I need it with me all the time.

I don't know about the rest of you ladies but the new jeans they make have barely any pockets.

I found this thing at Findley Market. It is small and it has two pockets and one holds my cell phone and the other holds my remote. I live alone so I want the cell phone with me in case something happens and I have an accident or something. I keep the cell phone with me all the time and I used to be able to put it in my pocket but there are no pockets on these jeans anymore.

>> I think one way to decide on accessories you look at your life. If you like to watch TV, the TV streamer might be important.

If you like one on one conversations or if you like to go out to eat, then the mini mic would be important.

The phone too. You can buy those. You can see what the price are and get the ones that cost the most and order the others separately.

>> There is a blog out for people that have hybrids and there is a lot of helpful information that comes out there. I don't have a Costco membership but they said you can buy the wireless accessories at Costco cheaper than you can your audiologist. You might want to look at that too. Maybe order the ones that are the most important to you. Like I said, your mini mic can be used sort of as a TV streamer. I plug mine into my small TV upstairs and it works very similarly to the TV streamer. You probably, maybe it refines the audio a little more with the TV streamer. But, like I said, with my son and daughter-in-law using my main TV, I have not been able to use the streamer a lot yet.

>> I wonder if it would be helpful to people like Yvonne and those who don't have one yet, if we wrote down the accessories on that board and everyone could go by and put a tick mark by the one they have and these folks could see what the most popular ones are. I know at the picnic at Brian's house that was a few days before I was activated. I learned from talking to those people what were the

most popular and most helpful accessory.

Unfortunately I had ordered them but I could change my order at the last minute.

They were wonderful about swapping them out.

>> What do you have?

>> I have the phone mic and I had not ordered that. Only when I talk to Deb Turner said this is the most important thing I have. So I got that. I did not get the TV streamer and I was kind of concerned I was missing something by not having that. But, now based on what you said, I know I can use my mini mic into that. That is great information I am so happy you shared that.

>> People should know when you go for your second implant you can get the other ones.

Also it really depends on your lifestyle. Are you a person that watches a lot of TV or never watches TV.

>> Do you use your cell phone?

>> Do you have a lot of friends and talk on the phone or could you care less. It depends on a person lifestyle.

>> So the three items that you choose, is that all included?

>> Yes.

>> I think the audiologist will tell you what your choices are. Like Sister June said the remote is an option. You have to look at what options are there and which ones you need. The remote really should be important. Also if you get the second implant you can order what you didn't get the first time.

>> I just got my second six weeks ago and she told me I could get all four and I got the four from the beginning. The mini mic, TV streamer, remote and the cell phone -- just so I had them all. I wasn't sure I could use them all but I have

used them all. Your audiologist can help you with that point.

In the beginning you don't know if TV is more important or telephone more important. You are not sure. I found just by telling her I wanted all it helped much much better.

>> What does the remote do?

>> The remote has -- the audiologist will put different programs on for you.

Depending upon what she thinks is going to be useful.

Sometimes they only put 1 or 2 on in the beginning and they can add some. You can have as many as four.

Just by pressing these buttons you can change from one program to the other.

For instance, the program on mine that says home is more open to what is around.

The cafe cuts out some of the background noise.

Groups cuts out a little more.

If I go to music it opens it up to everything. If you are listening directly to music you don't want to miss some of the nuances in it.

Also you can adjust the volume, the sensitivity which is how far out you want to pick up sound.

If you go on you can -- you have this set so you can pick up -- if I am using mini mic I have to press this so it picks up the mini mic. It kind of in a way you can term it pairing. But then there are other different settings on this thing that you can go into.

>> It can be a little overwhelming. Some audiologist will start you out with two programs. The home programs or the everyday program. What is your everyday listening situation? My everyday listening situation is pretty quiet.



Mine is set a little differently than someone that is around a lot of noise.

The program is unique to you.

The second program she would probably give you is cafe. Noise program.

When you are out at a restaurant and want to be able to control the noise you can turn the volume down.

All the other things you learn as you go along. They don't throw that all at you at ones.

>> So it adjusts what you hear. It is like controlling the dial on the radio.

>> The scan program now, the people that never had an implant prior to the scan, a lot of people like the scan program. It direction it for you in each situation.

Some people never look at remote. They are happy with the scan program.

>>. Yeah. Those of us with implants have the choice of adjusting our hearing unlike hearing people.

If I go to my back porch at night and want it to be a little quiet. There are air conditioners running and there is traffic on rapid run road. I go to the remote and go to sensitivity setting and turn it all the way off. I don't hear any traffic noise and I don't hear the AC's running but I still have the volume up so if someone comes out on the porch to talk to me, I can pick that up. There are pluses.

>> To clarify, so you turn sensitivity down to run?

>> I turn it so it doesn't even have a bar anymore. So I am not picking up anything very far.

>> Then you turn volume up?

>> If it is a normal setting I may leave it alone.

>> If you don't know what sensitivity means. If you are in a group like we are here, you want to talk to the person next to you and everyone else is chatting, you

can put your sensitivity down and all the other voices would begin to fade and you would hear the person next to you.

On the other hand, if you want to hear what everyone is saying and you can't hear Mary Jo because you are sitting over there you would increase your sensitivity.

The lower it is the closer the people. More people you make it larger. The volume depends on how loud or soft you like it.

When I go to a restaurant I put my noise program down to 1 or 2 and I put my sensitivity down to like a three. I don't use my mini mic and I can hear the conversation better than some hearing people. I am able to block out some of that noise that the hearing person can't.

>> How do you use the implant to listen to a land line phone?

>> You put it up to the mic.

>> Do you do well with it?

>> Do you use T-coil? I don't have phone clip on this ear yet and I carry on conversations well. When I get my N6 I have three ways to do it. I can listen and put the T-coil or use the phone clip.

>> I don't think you can pair a phone clip to a land line phone?

>> The land line has to have a blue tooth. There is a phone that has blue tooth capacity in the land line.

>> So you do hold the phone up to the device?

>> Yeah. Where your mics are. You will be able to tell. You get used to it.

We call it a sweet spot. You move it around until where you find it is the loudest and that is where you hold it. You are not picking your sound out of your ear anymore it is from the mic.

Now, I have caption phones on my land line. You can I think now you can get

one caption phone for free. The captioning is free. It is a price that is spread out on everyone's land line expense. They are a help. A lot of it depends on what caption typing.

Sometimes it is really good and they are close to the conversation and other times they can be miles back and it is useless. I don't think it is computer.

Some maybe but sprint isn't and that is what I have.

>> Do we have other questions that they would like us to answer or talk about our experiences.

>> Do you want me to do --

>> Do you have questions?

>> At first they wanted to give her the -- she has a tumor and needs MRI's once in a while. We talked to Greg and said cochlear will take out to do MRI, the strong MRI, they will have to take the magnet out in order to get a good reading. No one has really told us how many systems there are? There is more than one I assume? The cochlear implant there are different kinds?

>> Three different companies. The cochlear America is this. Med al and advanced bionic s.

>> You need to have a conversation with your surgeon.

>> Yeah, they agreed.

>> When we talk about it we are talking about our product. There are other companies. When they say cochlear they mean cochlear America.

I don't really need an MRI, I don't want any more now.

>> We have a sister that got MRI, she had implant 15 plus years and she wishes now she had cochlear.

>> We've been to the other meeting and I think this is a better system.

>> I think biology and the ear sometimes doctors recommend it is a better product. They are all good. You talk to anyone with a Metel or Advanced Bionics they will all say the same thing.

Talk to people. For myself, I knew about implants hybrid 5 to 8 years they were around but I was not psychologically ready. I got to a point where I couldn't hear on the phone and I was using my assisted listening devices and I would have a headache after the meeting and it was time. Everyone's journey is different.

>> Did you have a lot of pain?

>> Personally, myself, no.

>> I did the first time but not the second time.

>> If you get cut you will have a little pain. Not a lot. You will want to sleep a little more because you had the anesthesia. Some people go back to work in three days. It really depends on the people.

>> I guess the one thing, I didn't have pain and it was fine and surgery was great and everything. But you are putting something -- maybe you have worn hearing aids but sometimes it takes a little getting used to. It is just more of an annoying ache that goes away.

>> I wear hearing aids so I am used to that.

>> I have a question about your recommendation on how quickly you get the second unit? What does that seem to depend on? Are there any thoughts on that?

>> I know that I can speak for Brian, he went six months, he wanted it. Some people want them both at the same time. Some doctors will do that and some will not. For me I waited a long time because I was waited until I was 65 so Medicare could pay for it. I was doing well. When I went to get tested -- this

ear never had a lot of stimulation and it was totally dead. I said what do I have to lose like Mary Jo said. I went out to eat that night I was activated and the batteries in this side died and I didn't have replacement. It sounded funny but I could carry on a conversation with an ear that was dead but now activated. With my speech reading and I had an enjoyable evening out with my friends.

Do I hear as well out of this ear as this ear? No. But could I survive and live and converse? Yes.

That is the advantage of having a second one. Besides the balance hearing and all of that. There are times when the implants do fail.

>> What determines the second one and how do you get it paid for?

>> If med -- if it is a medical necessity they should pay for both.

I would imagine most audiologist would encourage to you work with the first one. When I found out I could upgrade both, I asked the audiologist if I should do them together or separate? She said you can get this one quicker and get it and get used to it then you will be ready for the second one.

That is what I did. By the end of the week I had my second upgrade. I went from N5 to N6 on this side. Actually no problems at all. I put it on and gave me adjustments and I was good to go. It sounded fine. I just had new gadgets to play with. The N 22 is different. I will have a story to tell at the next meeting on how I am with the N2 and the N6.

>> You said you had 2 and 1 is not as strong as the other?

>> In 1996 the technology they called the N22. The inside piece -- consider it like a computer chip. The computer chip changed when I went to the N24. I have a different chip on each side of my head. They work well together right now. But I am curious what it is going to sound like because the internal piece is

different. I don't know. It can be perfectly fine or maybe I will go back to Mickey Mouse again. I really don't know. It is a request in my mind. The N 22 was approved this summer. We can get up grade September, October 1st. The N22 -- thousands of us have been waiting for this to upgrade. There will be a lot of posting on Facebook and chat pages about how people are doing with it.

>> I heard everyone talking about upgrades. Does insurance cover the upgrades too, later on?

>> Every five years Medicare will upgrade you if it is a medical necessity. If you are not Medicare aid, insurance companies follow what Medicare does. The base line is five years. It usually takes technology about that long to -- right now, cochlear is always working on the N7.

>> I am on Medicare but I was due for an upgrade but I was turned down because insurance wouldn't pay for an upgrade.

>> Was it five years?

>> I got the freedom before the five?

>> What year did you get the freedom?

>> March of 09.

>> You should work with cochlear reimbursement. That is five years.

>> It is going to be about seven years. So --

>> If your last upgrade is older than five years ago you should be able to upgrade.

>> I had a bad processor and the speaker was bad as of five years. We tried to upgrade and insurance said they would not, they would rather re place or repair it instead of up grating.

>> Can you appeal. Pretty soon the freedom is going to be obsolete.

I don't know who the audiologist is but work with her to see if she can help you or

contact cochlear company and see if they can help you with that.

Are you coming to the zoo next week?

>> I am thinking about it.

>> There will be someone from the cochlear Denver office there. Her name is Perry. I would encourage you to come.

>> The last two years I have been turned down.

>> Sometimes you just need to push and push.

What other questions do we have?

>> Medicare pays for the operation but not the device?

>> They pay for the device?

>> How much is the device?

>> Close to \$10,000.

>> So they pay for the operation and the device?

>> Yes.

>> I was under the impression they only paid for the surgery.

>> I have a secondary insurance, I have never paid anything for either one of them.

>> I didn't either.

>> I have Aetna for Medicare coverage.

>> Medicare part D, it depends on what Medicare plan you have. You can talk to the people at cochlear at the zoo next week, there will be people there to talk about that insurance if you have questions. I am not qualified to answer all the insurance questions.

We have another piece that Mary Jo wants to talk about.

Lou Ann and I in September went to Louisville and hearing loss association of

America HLAA. The Kentucky district had a conference for a week end. Those kinds of things are really fun to go to. They are built and planned for people with hearing loss. Every session, the room had a hearing loop so you could just turn on the your T-coil and you had the sound and speaker right into your processors. If you had a hearing aid with T-coil you had everything coming right through your hearing aid.

They all had a loop. They also had CART. There was the words you can read like here.

Also, there were some people who were deaf and didn't have an implant or hearing aids and so they had someone signing all the sessions. It is really neat to go to something like that when it is geared for us instead of going to something for those with hearing and trying to adapt.

They had a lot of different sessions. They had one on hearing dogs. We just got in like the last 15 minutes of that but it sounded like it would be really interesting. It was a woman who trains these hearing dogs and they will alert people to the phone or doorbell or if there is a -- a lot of them have sounds and if you miss the signal and you were going to walk the dog. It was very interesting. They had how to advocate for yourself. What the federal laws are. For instance, if you are still working, what does the law require your employer to provide you with so you can do this job. That was pretty interesting.

Then they had another one, this was all Kentucky, Ohio doesn't have an advocacy branch like the government does in Kentucky.

But, told you which group in the government to go to for different problems. That was, like I said it was all Kentucky and Ohio doesn't have a lot of that type of thing.



If anyone is looking for a passion you might want to start working for something like that. It was interesting on what all Kentucky and -- they had a market place and cochlear had a booth and so did Met AI and Advanced Bionics. A lot of things you can get. I had a strobe system at home for alarms. I have one little box and I take my cell phone and set my alarms. I put my cell phone attached to this box and it activates a bed shaker when an alarm goes off.

They had a thing there that will -- I have not set it yet, but it will take all the alarms I have set on my cell phone and it will -- if one goes off it vibrates on its own. I can change it by changing my cell phone. So if I am traveling I can just take this one little round thing and set my alarms on my cell phone and I can put that thing under my pillow or where ever I need it and it will vibrate and wake me up. They had a lot of different things like that. It was fun to walk around and talk to different people and see what they had and how they worked.

The guy that did the looping on the session rooms he had a booth there too. Europe is way ahead of us on looping. Most of the public places like -- you go to a movie or play or something like that. Those things all have hearing loops. Churches have hearing loops. We don't have that yet. We are struggling on that.

>> Kim Combes an audiologist that visited our group. Told us Sarasota, Florida is the most looped city in the US.

>> We can all move there. Sounds good to me.

My son is looking into what it would take to put a loop in our church. That helps not just those with implants, I am the only one with implant. But most hearing aids --

>> All of the hearing aids --

>> Have T coils. It would benefit many people in the congregation that have hearing loss.

The other thing that was really good, the main speaker, the last one on Friday was Justin Osmond. He is a nephew of Donnie and Marie Osmond. You can see the resemblance. He was awesome. He was born deaf. Two of his uncles and siblings of Donnie and Marie were born deaf. The two older boys needed hearing aids and they were expensive so as we all know -- so they started singing as kind of a benefit thing to earn money so the older boys could get these hearing aids. It just kind of built on that. He was a very inspirational speaker. They did not diagnose him until he was two years old. He was behind socially in language and everything.

What they had to do to try to help him catch up. They told him he would never be able to play a musical instrument. Here he is in this musical family and he plays three instruments.

If you -- the book is called "hearing with my heart"

It is by Justin Osmond. I will lay it over here if anyone wants to look through it. I started reading the book this last week and it is very very good. He spends a lot of his time now going to -- all over the world to help these children get hearing aids. He talks about how amazing it is, these children that have never been able to hear. All of a sudden the expression and joy on their face. If you have on Facebook you have seen the movie of the little guy that has his cochlear implant turned on the first time and hears his mother's voice. He is really an infant but the look on his face is priceless.

>> Some of those --

>> That is what he does with his life now.

>> The videos you see on you tube, they are nice. But remember, they are a baby. All he is hearing is noise. He has to learn the language just like any other child. If you activate a child at three that has never heard, he is an infant. He is not three-year old hearing he is an infant. So there is catch up to do.

>> In case anyone gets frustrated and thinks your speech improvement is not going quickly enough. They say it takes an infant an entire year to begin to make sense out of all the language and sounds they hear. So, when you get impatient with yourself because you think you are not moving forward quickly enough. Remind yourself.

>> I said it took a good year to hear sounds. There were still things I would hear and say what is that. It was like you were not sure what it was. It is a work in progress is the only way I can describe it.

>> I had a request of all of you. A couple months ago we had a survey about things you would be interested in. People were good and filled it out but they checked everything on the list. So that wasn't that helpful. We want to focus on what you are really interested in.

So, I have these little smileys and I want you to give me your first, second, third, fourth and fifth choice. I want you to say your top five choices of what you want to here.

Those that are spouses and friends, we would like you to fill it out also. You don't have to have an implant or hearing. Anybody. You may have different interest an your spouse.

The yellow is your number one choice. The green is second. Red is third choice...

>> The captioned telephones, a friend of mine gave me places to look at. But they don't seem very practical. You have to get a set or something and it is not like you just plug it in and see what people are saying on their phone. You have input on the caption telephones?

>> My caption phone has a little screen on it about like that. You plug it into the phone line and you do need to set it up, at least mine, with the Internet. So, there is a -- it tells you exactly how to do that. It is not that difficult, I did it.

>> It is practical, you think?

>> Yes. It is hopeful for me when someone calls my land line number. There are some people no matter how hard I try I will never be able to understand them. They have a maybe very high high voice and I have -- that is where I have a lot of my difficulty. Some people can't -- just don't pronounce their words well. My sister is one. I don't know if her dentures don't fit or what.

>> I can't hear women.

>> Even sometimes the person doing the captioning has a hard time understanding her. Without captions I would not be able to talk to her. I think it is good in certain situations. Like sister June said, you have to look at your lifestyle.

>> Do you hear better on cell phone versus land line?

>> Definitely because the cell phone wireless piece, it makes a huge difference.

>> Sometimes when I have the cell phone I think I hear well. Actually -- I think they have Tang pains with the cell phone to get the quality of sound really good. On the land line phones anymore, since it is not like bell labs. Anyone can make a phone. They are so concerned about getting all the gadgets on there that they are not concerned about the quality of the sound. I think it has deteriorated

something awful.

>> That is probably true.

>> The quality of the sound isn't their major concern anymore. Even with my caption phone, I don't think the sound quality is very high. With my cell phone, and even without the phone clip I do better with the cell phone than I do with a land line. But the phone clip, wireless piece makes it phenomenal.

>> I still have a business and I have to use the land line a lot. Cincinnati bell doesn't seem to offer anything -- Cincinnati bell doesn't help you with much of anything.

>> Not anymore. They kind of lost their way.

>> It is not just Cincinnati bell, I think since like AT & T and all the break up. It is totally different. The customer care isn't as great of concern anymore. It is a mess.

>> You would think they would be offering products.

>> You would think but they don't. When I -- the software firm I work with, we maintain Cincinnati bell records and database. We worked with them a lot. They really don't make any effort to sell any kind of things for hearing impaired. When I was working --

You would think Cincinnati bell would be partnering with them. With the aging population. You would think they would be right on that. It would be good PR.

>> They don't seem to have interest anymore.

>> They are really not --

>> I had this little thing when I was working and it connected I think to the receiver and into the telephone but it allowed me to increase the volume and tone a little bit. It helped me for a while. I still -- in the beginning of my hearing I used

those and that helped a little bit. But they were not Cincinnati Bell products.

They just don't -- they don't offer anything.

(Individual conversations)