My Cochlear Implant Journey…

By Donna Woods

October 7, 2019

One week from today I will be receiving a Cochlear implant. I am excited, nervous, anticipating and grateful.

How Did I Get Here?

I started noticing what I thought was some slight hearing loss in my late 40's. At that time I was working with the Warren County Health Department. The office of the audiologist with the Commission for Children with Special Health Care Needs was located within our building. I ask that person to screen my hearing and the result showed some slight hearing loss.

In my 50's, my hearing deteriorated some. I tried hearing aids twice and returned them twice. It seemed to me that my hearing was not improved enough with the aids to justify the cost. I felt I was managing well without them in both social and work settings.

I had the good fortune to retire from my nursing career at the age of 58. During the 2000 census, I worked in the census office with many others making calls to persons about working for the census. The office was huge with high ceilings and with all phone calling persons in the same room. I struggled each day to hear on the phone. My stint as a census call person was brief.

In the meantime, I was very fortunate to have a young Grandson and the time to enjoy that Grandson. Our Grandson lived a couple of hours away from us. Since my husband was still working, I became the Grandma Uber. To my dismay, I was unable to understand that wee voice in the car and out of the car.

In my early 60's, I purchased and kept "in the canal" hearing aids. I hated them. I always heard my voice as tho I was in a barrel. My hearing was somewhat better with them. So, I persisted and wore them regularly. After five years or so, my hearing loss increased beyond my hearing aid capabilities.

My second hearing aids were "behind the ear" aids. I liked them much better. I paid a higher dollar for them to be able to have the benefit of an FM system. I was very active in volunteer work. The FM system was invaluable for my use at board meetings and other group situations.
I acquired my third pair of hearing aids when the FM system in my aids no longer worked and the repair would be costly. These were also "behind the ear" aids. I opted to not purchase a brand with FM capabilities in order to keep the cost lower. I did activate the telecoil and began using it in a variety of situations.

I felt that my hearing was stable for a period of time.

For the last two years, I have felt that my hearing has been decreasing. But..my hearing evaluations at my hearing provider have not seemed to be much different. I have tried aid adjustments and hearing aid molds. All without feeling much of a hearing difference.

Yes, I was hearing but my word understanding was decreasing.

Last fall, my husband and I attended a seminar in Bowling Green Kentucky regarding cochlear implants. At that time, I did have some basic information about implants. I had read educational information in my Hearing Loss Association of America magazines and had known persons with an implant. We attended the seminar because I was becoming increasingly concerned about my inability to understand words.

Now that my husband and I find ourselves in our 70's, we were pleased to know that there is an ENT surgeon in Bowling Green who is skilled with cochlear implant procedures. Trips to Louisville or Nashville would not be necessary for the pre and post office visits as well as the surgery itself.

The seminar was helpful and put us in contact with resources for further investigation.

I spent several months reading everything I could find in print and on the internet, talking with implant recipients, and talking at great length with my husband. I made it known to anyone who would listen that I was thinking about an implant. Doing this outreach proved to be successful in locating recipients to speak with about the many questions I had.

The next step was an appointment with the ENT surgeon. My husband and I went to the visit with 2 pages of legal size paper full of questions. The surgeon was wonderful. He sat quietly, not acting like he had other things to do or staring at a computer screen. He looked me straight in the eye, spoke clearly, answered each question.

Then the audiology visit was scheduled. There is a hearing loss criteria to meet in order for Medicare to pay for the implant. I guess it's the first time I've hoped that I would fail a hearing test in a huge way. And sure enough I did. Even tho I can hear sounds, my word comprehension is very very bad. Aha! I thought so! It was comforting to have confirmation of what I felt was happening with my hearing.

Another visit to the surgeon to answer any remaining questions and to schedule the surgery.

So---Here I Am, One Week Before Cochlear Implant Surgery…

I don't really know how long my hearing will be impaired and in the process of rehab. What I have learned is that each person is an individual when it comes to the restoration of their hearing. The rehab is very dependent on the individual and their faithfulness in doing the rehab work. Since I tend to be fairly OCD about this kind of thing, I feel that I will make the rehab work for me.

I am finding these pre-op days full with things that would normally be spread out over the fall season. I don't want to be trying to get things done when my hearing is compromised. And little things need done like, coloring my hair and getting a haircut…a head incision would for sure hinder that for a while.

My Realization Is This…

If I continue with aids, my hearing will continue to decrease. If I have an implant, it will stop the hearing decrease in that one ear. And actually the possibility of the hearing in the implanted ear becoming better than now is very real. That's a very exciting possibility!

I'll be back with you after surgery to let you know what the rehab time is all about!! Till then, enjoy the fall and take care of yourself!

October 13, 2019

Tomorrow Is THE Day!

Tomorrow is THE day! I couldn't wait till after surgery to record some things that are happening. Everything has been moving along as planned…pre op paperwork done a couple of days ago, groceries bought, laundry done, indoor plants watered, etc. Then the mail came yesterday morning. Now you have to understand…we pay bills by auto pay, check our bank accounts and credit card account online, and do most all business online. Our mail usually consists of money requests from various nonprofits and advertisement circulars. My

checking of the mail is pretty haphazard and can occur over a couple of days. Hmmm…something from Humana, my insurance. And then the BOMB dropped…Notice of Denial of Medicare Coverage for my upcoming implant! I cannot explain the immediate emotions that overcame me. We spent the next few hours trying to contact my surgeon. Finally this afternoon, we found each other. "What is happening" is our most pressing question! The doctor told us that he has received a letter of consent for the surgery and an authorization number. He gave us that number and we ask for a copy of the written consent from Humana. He will provide that to us. His Humana letter is dated October 10 and my Humana letter is dated October 8. I am going to place a little faith that it is all ok. My emotions have been all over the place and I still am feeling jittery inside. I'm trying to focus on the bigger picture.

October 14, 2019

The Day Has Arrived!

THE day! The pre op appointment a few days ahead makes everything smoother and quicker on the day of surgery. All the nurses, anesthetist and Dr. Ebelhar have been wonderful, caring, professional. The surgery itself was 2 hours in length with post op recovery uneventful. We were home by 2 pm. I did have some brief nausea and dry heaves, very brief. I have a large helmet like bandage on my right side covering my ear and much of head on that side. I can't wear my

glasses because of the helmet and that is an obstacle for functioning. I have discovered a way to "stretch" reader glasses so that I can read by holding them in place. I have very slight discomfort in the right ear area but nothing to even take any medication about. I do have a lot of dizziness and that is another obstacle to functioning. One of the persons I talked with prior to this surgery told me that

she had dizziness for a week or so. So I'll just deal with it. I do have a slight sore throat from surgery intubation but was prepared that I would have this. I am eating very lightly and keeping my hydration going. I'm sleeping for 2 hours at a time, getting up to drink 8 ounces of water, going to the bathroom and back to bed. Rest seems to be the thing I want now. When I am up, I use my hearing aid in the left ear. That is somewhat helpful for functioning.

October 15, 2019

Day 1 of Post Op Recovery

Slept well in 2 hour increments last night and most of this morning. Still eating lightly and continuing good hydration. Using my makeshift glasses to email and text a few concerned family, neighbors and friends. Dizziness continues. No pain. This afternoon we removed my helmet and other bandaging, cleansed the suture area with peroxide/water and applied vaseline as instructed, no further dressing

is required. My husband is a great caregiver!!! I am surprised at how unobtrusive the incision is. It is directly behind my right ear about ½ inch above ear base and follows the base outline for 9 stitches. I don't think any hair had to be shaved. I barely can feel my processer under the skin almost immediately above the suture line. There is no pain when gently palpating it. Again no hair is shaved. Now that I don't have to have the dressing, I can wear my glasses. The ear piece slides nicely between the ear base and the suture line. What a relief it is to have my vision clear again. I have a feeling like my right ear is full of putty or bubble gum and my right ear feels numb like when you have your gum numbed for dental work. No pain. Dizziness continues. I am up for longer periods of time today, reading, watching some tv. Have moved to eating soup, crackers, peanut butter.

October 16, 2019

Day 2 of Post Op Recovery

Today I had some relief from my dizziness. Took a meclizine tablet, laid down for an hour and was able to function somewhat throughout the day doing not much of anything. I had tried the meclizine yesterday without any relief of dizziness. Issue today is with quick head movement or movement of eyes. I do have a long history of Meniere's disease and of positional vertigo. I'm beginning to wonder if I should be doing Epley maneuver exercises in case it is positional vertigo. I'm thinking that I'm better though because I requested a hot chai tea latte and a pastry of any sort for supper!!

October 17. 2019

Day 3 of Post Op Recovery

Didn't sleep well last night. I'm quite sure it had to do with the chai tea latte and caffeine overload. Today my dizziness is worse and not relieved with meclizine. This is causing some feeling of slight nausea. Never the less, I made myself shower, put on makeup and go out for lunch for the first time post op. It is a beautiful fall day and Darrell and I sat out on the swing for a nice period of time. I need very badly to know if I should be doing Epley maneuver exercises for my dizziness. I'm afraid to do so without doctor approval. Would be awful to "undo" this major surgery! Darrell tried unsuccessfully 2x to make doctor contact. In other aspects, my incision is healing well, my "ear full of putty" feeling is still present, my energy level is still not up to par.

October 18, 2019

Day 4 of Post Op Recovery

My dizziness is still raging but at a slightly less drama than yesterday. I did take a meclizine about 5am this morning and find that I now have a "hung over" feeling plus the dizziness. Spent most of the morning up and down to bed. Darrell tried again to contact the doctor and finally was successful. Doctor says that it's ok to do Epley maneuver exercises if I wish. He doesn't think that it is necessary

though, that this dizziness will subside at some point. Maybe I'll wait for exercises. They make me so dizzy on top of the already dizzy!!! Afternoon was better, dressed, makeup, out to eat dinner, enjoyed swing sitting. Right ear plugged feeling only slight. The top of my right ear has felt numb all along like when I get my gum numbed for dental work and continues to feel that way. I'm grateful to have the very slightest hearing in my left ear by using my hearing aid.

October 19, 2019

Day 5 of Post Op Recovery

Ok…this dizziness is really affecting my ability to move on and gain some recovery. Today I started my Epley maneuvers…3 sets 2x for the day. I also started resting and sleeping on the couch with head elevated. If any of you have had BPPV (Benign Paroxysmal Positional Vertigo), you know that Epley maneuvers and not lying flat are gospel requirements for improvement.

October 20, 2019

Day 6 of Post Op Recovery

Slept on the couch with head elevated last night and for rest periods today. Epley's 3 sets 2x for the day and noticing some improvement. Thank goodness! Still must move eyes, head, and body deliberately to decrease dizziness episodes. Cooked some homemade beef veggie soup tonight, first time at the stove for this week. Keeping fingers crossed for continuing disappearance of dizziness. Incision continues to be healing nicely. Right ear still numb with intermittent feeling of canal fullness. So thankful that I can hear somewhat with left hearing aid.

October 21, 22, 23, 2019

Day 7, 8, 9 of Post Op Recovery

Continuing Epley maneuvers 3 sets 2x each for the day and sleeping on couch for naps and at night. Dizziness has improved to level where I am mostly dizzy free for the day. I do keep body and head movement slow and deliberate. I am up most of day with an afternoon nap, enjoying being outside with beautiful fall

weather, walking some, watching movies in the evening with captioning, and basically taking it easy.

October 24, 2019

Doctor Post Op Follow - Up

Good to see Dr. Ebelhar and get his input about my progress. Stitches have mostly dissolved. Incision healed nicely. Yay!!! I can wash my hair now! These are some of the things we discussed and explanations from my Doctor:

Ear plugged feeling…there is some old blood behind my ear drum that will absorb in the next couple of weeks;
Numbness and slight swelling of right ear rim…created by surgery and will disappear in the next couple of weeks;
Taste buds effected…created by surgery and will disappear eventually;
Dizziness…will disappear in the next week or so, may continue Epley maneuvers if desired;
Exercise…may restart exercising, begin at easy levels and gradually increase.

My activation appointment will be in 2 weeks. The audiologist will call to schedule that appointment. Will see Dr. Ebelhar in 3 months. If everything is good medically, will return in one year.

Random Memories of My Hearing Loss Just PRIOR to My Implant...

I want to think through some of my memories before I go any further in this hearing journey. These memories will be random and written in a mish mash style:

Attending meetings and not understanding what the speaker was saying most of the time even with microphone use. Improved some after I got my FM system and ask speaker to use my transmitter. **Never understood the questions from the audience** and was at a loss if the speaker did not repeat the question.

Traveling and not understanding the travel guide. Was able to use my FM system at times.

Going to a party and being able to have one on one conversation but not able to keep up with group conversation…exhausted after group get together. It didn't matter where I placed myself in relationship to the group. I still couldn't understand most of conversation or keep up. Slowly began to withdraw from group events.

Inability to understand retail clerks…had to ask for repeat of words or just guessed at what they might be saying. Same with servers.

Gave up on phone conversations until I got my cell phone blue tooth…able to hear mostly ok with that set up. Had tried amplified phone and captioning phone with no success. Learning to rely on text and email heavily.

Took a pottery making class and really struggled…instructor very soft spoken and moving around room to help each of us. I explained several times that I am hard of hearing and needed him to speak louder and clearer. That would last for a minute and then he would return to his normal pattern of speaking.

Difficulty understanding my husband who speaks quickly, not clearly, doesn't look directly at me and has a mustache/beard. We have discussed this many times.

Difficulty understanding airport and inflight instructions. Difficulty with any group instructions in any situation.

Unable to enjoy my favorite exercise, yoga, until I started attending a class with a looped room. Impossible to enjoy yoga meditation without hearing assistance.

Very difficult for me to understand my ethnic friends due to language accents. Tried to take a Spanish class but was not successful due to inability to distinguish language nuances.

Theater movies impossible without captioning glasses. Television viewing impossible without onscreen captioning or use of my infrared/telecoil set up. Attendance at our performing arts theater very difficult to understand spoken words…hearing assistive equipment inadequate.

Difficulty understanding our financial advisor who speaks very quickly.

Rooms with high ceilings and hard floors are so difficult.

There may be more but this is all I can recall at this point. In general, understanding words has become a very tiring, frustrating for me and everyone, exercise in communication.

I will return to my journal entries at implant activation time. Looking so forward!!

Oct 28, 2019

2 Weeks Since Surgery

Incision is tender---applying cocoa butter to soften incision area, a couple of stitches still present.
Ear rim no longer feels numb but seems somewhat swollen still.
No dizziness.
Still easily fatigued.
Have not driven…afraid I will not hear well enough to be aware of emergency vehicles or any other warning signs.
Going out every day for lunch as normal for us, cooking suppers, cleaning house, doing laundry, working in yard…pretty much back to normal on those things.
Managed to do a couple of retail transactions yesterday…didn't really understand what the checkout clerk was saying but stayed focused and followed the cues.

Nov 4, 2019

3 Weeks Since Surgery

Top of ear rim, top of incision, and bottom part of implant feels tende.
Feeling of ear canal being plugged comes and goes, get a popping sound when I yawn sometimes like when you have wax in your ear canal.
Energy level has returned.
Still not driving.

Have not heard from audiologist as yet for activation appointment…that's actually a good thing since I have remaining tenderness…I'm thinking that external apparatus would aggravate the tenderness right now.
Able to carry on a one on one conversation somewhat successfully using left aided ear but have to be right up face to face.

Nov 11, 2019

4 Weeks Since Surgery

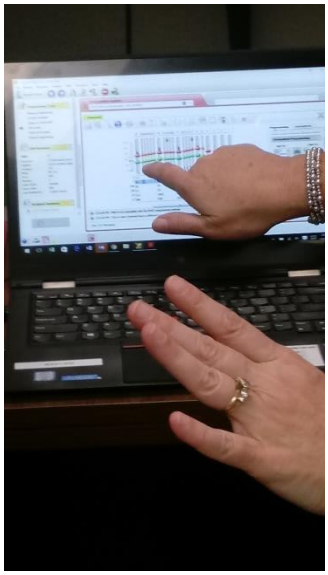
All tenderness gone except for top of ear rim and area where my ear attaches to my face. I think this is aggravated by my glasses.
Feeling of ear being plugged is mostly gone…only occasional brief sensation.
Taste buds still not up to par.
Energy back…doing exercises at home.
I have gone to several social settings in the last week using my left aided ear to hear…room noise is overwhelming…group conversation next to impossible…I continue to be able to converse with someone if they are right in front of my face so that I can also lip read.
Still not driving which is a personal choice…others might go ahead.
Waiting to hear from audiologist for activation…I'm ready!

Nov 15, 2019

Activation Day!

Here it is…the Day to find out what this is really all about! I have not been nervous or excited until about ½ hour before leaving for my appointment. At that time I became so nervous that I felt nauseated! I have had activation described as an overwhelming moment. I've had persons tell me that on activation they heard voices and sounds as robotic, metallic, cartoon like. My audiologist showed me my external equipment and placed it on my ear and over my internal magnet. The equipment is not heavy nor is there any "pull" on my skin as the magnet is placed or removed. In fact, I didn't even know that it was in place. The ear piece does not interfere with my glasses ear piece. **Then….the moment that the equipment was turned on or activated. All of a sudden I had tinnitus on steroids!!** If you don't experience tinnitus, I will describe the sound I heard as a

100 wind chimes going off in my ear. My audiologist's voice sounded normal but very very distant. After fine tuning the computer to decrease the ringing noise to a tolerable level, the **mapping** began. This is a computer process that the



audiologist does to set perimeters for what is going to be my listening range until I return for my next appointment. Adjustments to the range will change as my hearing advances. I was given a large backpack and a smaller one full of accessories and booklets, including a "Adult Home Based Hearing Therapy Manual". My audiologist will monitor my progress but I am in charge of my rehab. When I left the office today, I was feeling fairly overwhelmed but excited to be on the next steps of this journey.

Nov 17, 2019

2 Days After Activation

I have to keep in mind that there is a huge difference between acoustics treatment and electrical treatment or the difference between using hearing aids and using an implant. My audiologist asked that I use my right implant without my left hearing aid as much as possible. I am finding though that I can't hear voices loud enough without my aid to distinguish any word meanings. With the aid, I can tell a fair percentage of the words. I now notice that the tinnitus sounds in my implant ear are connected to environmental sounds. It occurs or increases/decrease with words or any other sounds such as my typing at this time. It will be interesting to see how this morphs into acceptable sounds in the future. I did notice today that using both my aid and my implant that I was able

to hear completely the music on our truck radio, not the words but the tune. I have not heard radio music for a very long time. I continue not to understand conversation unless one on one and directly in front of me.

Summary of Week 1 Post Activation

It has been an interesting and challenging week. First of all, activation day is a busy day. Most importantly it is a day to get external parts of my cochlear system and to set a starting point for sound processing. As I understand, this starting point is different for each person. I can only tell you then what it was for me. My starting point was to hear a lot of vibration type sounds, high pitched, and similar to chimes. I did not hear words unless using my aided ear. Without an aid and only the processor, I had very little awareness of words. I also received many, many accessories, replacement parts, booklets, pamphlets, and printed instructions. To say the least, I have been overwhelmed all week with the quantity of things, and I haven't gotten a grasp on where to start with it all.

My audiologist is wonderful! She stressed that the most important thing right now is to begin slowly. All the accessories will not even be addressed until I get some grip on beginning rehab. Today I found an empty drawer to store all my cochlear accessories. I have been frustrated with my attempts to set up an account with the Cochlear website and also to sync my cell phone with the Nucleus Smart app. I finally emailed the regional Cochlear representative for assistance. She explained to me that there needs to be some system requirements arranged by the Cochlear persons before I can access these two things. These persons are to contact me when this has occurred. Actually I don't understand this explanation, but I will wait until next week to see if I hear anything.

On top of all this, I developed severe tenderness/pain over my magnet site, along my incision site and on my ear when using my processor/external magnet. The pain was not present when not using the processor/external magnet. After three days of dealing with this, we scheduled an appointment with my audiologist. She decreased the strength of my external magnet and the tenderness/pain has not been a problem since. There are 4 strengths of external magnets for this version

of Cochlear...#1 thru #4. I had been using #2 and #3. She decreased me to a #1 with success.

My hearing is changing some. I have to use my aid along with the processor in order to have any possible conversation and then it's fairly iffy. Using the phone is out of the question. I do try to have considerable time during the day using only my processor. I am beginning to faintly hear some words on a music cd when playing it during the time I am at the computer, and I do hear the music clearer. The voices sound strange but somewhat clear. The vibration/chime like sounds seem to be less aggravating or perhaps I am getting used to them.

I started driving this week. I could really have done this earlier but I was afraid that I might not hear any emergency vehicles. I am just making a point to be extra vigilant right now with my driving. Fortunately, my hubby is retired and more than willing to be my chauffer. I am looking forward to what this next week brings!

Summary of Week 2 Post Activation

I decided not to participate in some group activities, due to the Thanksgiving Holiday. I am just not ready for group interaction at present. One on one, face to face conversation remains my best communication at this point. I spent the week searching for what I am comfortable with for my rehab exercises. The Cochlear Hearing Therapy booklet and cochlear.com/us/communication-corner website for communication skills are not for me. Both require a partner and I would rather not use that method. My husband is difficult for me to understand under the best of circumstances. I also want to have the freedom to do rehab exercises on MY schedule and not have to fit around someone else's schedule. I do believe though that when I'm ready for phone and music exercises that I will probably use the Cochlear Communication-Corner. I found and downloaded a free rehab program

called Angel Sound. It seemed like something I could work with until I got into the actual programs to be used. I found the instructions complicated so I decided to pass on this for rehab.

I went to our library website. It has excellent programs to utilize at home per computer, phones, kindles, etc. for reserving and reading books and also for audio books. I spent considerable time trying to work through the audio books section. The Overdrive program is for use with a computer and the Libby program is for phone, kindles, etc. I tried to download Libby to my phone and discovered that I don't have enough GB space to accomplish that. So, I worked through the instructions on the library site for using Overdrive. I discovered quickly that I will have to use a headset to be able to hear well enough to use this source. After some frustration with my headset not working, I found that I needed to go into my computer settings to activate my headset port. The search was then on for an audio book that I might half way understand. Female readers were not understandable and many males spoke with an accent. I went to the children's section to see if I could find books with simpler words and sentences. It took a while but I found The Gooney Bird Collection, a second grade level series that I could fairly well follow along with. Don't laugh!! You gotta do what you gotta do!!

By the end of this week I am thinking that the vibration noise is getting somewhat softer, but it still overrides words. It seems that the words are 2 blocks away and the vibration is right on my shoulder. I have used only the processor most of this week and I am getting ready to start week 3 post activation.

Summary of Week 3 Post Activation

During the first part of this week I had a ''sinking spell''! I felt very "at drift'' .... ''what have I done?" I am not feeling like I am progressing with my rehab and am not really sure what I am supposed to be accomplishing at this point. I emailed my friend who has had an implant for several years, in order to get some words of support and advice. My question to him was, *"Do you remember what type of rehab you did immediately post activation?"* Also I said *"I don't have a clue what type of progress is expected at intervals and what are good ways to achieve that progress." "Being a goal oriented person who works best when understanding steps required to achieve a goal, I am not sure what and how much I should be doing right now.*" My friend advised a few things ... He said "Possibly you are

trying too hard... Look at Advanced Bionics and Med El for their rehab programs, these are open to everyone. It's okay to use whatever program that makes you comfortable...only do chosen exercise programs 1-2 hours a day and then do a normal day as if you are just wearing hearing aids...use your blog to look back on progress. Assess if you are better today than last week...you will hear better a year from now, you will hear even better a year from that...goals tend to be ahead of us...with cochlear implants and hearing aids, you need to be looking backwards...you can only tell where you are in comparison to where you have been''.

I am very grateful for my friends who share this world of hearing challenges with me! Feeling renewed, I did connect with Advanced Bionics "The Listening Room". This is the type of work that l am looking for. Using my headphones and processor at first, I worked through some beginner programs. I also spent some time with the second grade "Gooney Bird" audio book using headphones and processor. Later in the week, I worked with these programs without my headphones, using my processor and left aided ear. By the end of this week I think I am getting much less vibration with environmental sound. I heard my cleaning cloth wiping my glasses lens! My taste buds are improving some. I have used my processor with my left aided ear much of this week. Words are still very far in the distance, with vibration being right in my ear. I continue to do well with one on one face to face but find it impossible understanding in groups or noisy environments. I am getting ready to start week four.

Summary of Week 4 Post Activation

First of the week, l am understanding most words in the Gooney Bird audio book using processor, aid and headphones. By mid week I am using aid and processor. However, I only seem to be understanding words less well. One reader spoke quickly and was very hard to understand. At the end of the week, I am using aid and processor only. Word comprehension probably 60-70% as I get further into the chapters. I do have to close my eyes and really focus to understand the words.

Now using The Listening Room programs for study with aid and processor. I tried intermediate lessons but l am not ready. I went over some beginner lessons first time using aid and processor, second time processor only, third time using aid and processor. I tried to distinguish actual words versus "same" or " different''.

I watched a DVD movie in our den. I understood words somewhat with captioning, lip reading, and processor only...that's a first!! I didn't understand words, though, if I closed my eyes and just listened. I went to the movie theater and used aid and captioning glasses. I had to remove my processor because there was not enough room on my ear for regular glasses, captioning glasses, and processor. I was able to understand the movie with this combination.

Later in the week I signed out a library e-book. I started reading out loud to myself. I will see if this helps over time. This week I have used my aid and processor most of the week. It has been very difficult to understand words clearly with processor only most of the time. I heard my windshield blades wiping across the windshield!

Summary of Week 5 Post Activation

Audiologist visit on Tuesday was helpful…created new mapping, talked about frustrations, reassured. Audiologist encouraged me to use only my processor when working on rehab exercises…ok to use both processor and aid for most other daily activities. She will see me as often as needed.

New things that I am hearing…cars going by our house on our street, sounds like a leaf blower or weed eater…Darrell snoring from den to kitchen…furnace running…voices to the forefront of my hearing with no vibration overlap…do have an echo along with most sounds, some voices sound like they have swallowed helium, some sound high pitched…don't think I comprehend words much better as yet except one on one, face to face.

Summary of Week 6 Post Activation

Hearing voices as helium voices with background noise like a motorcycle or car running. Using processor and aid. Beginning to learn about accessories but will not actually activate any of them at this time. Had a couple of retail experiences that I was able to understand most of the words. Heard words on car radio at volume level 20 using processor only.

Summary of Week 7 Post Activation

Using processor only now. I realized Monday that I am understanding Darrell's voice better…he agrees. Most voices still have some helium effect but some are beginning to sound more normal. Background noises seem to be less. On Friday I did 3 face to face business transactions by myself and understood most all the words.

Summary of Week 8 Post Activation

Seem to be hearing words well this week. Audiologist visit on Tuesday…mapping adjustment made. Audiologist thinks I am doing well with my implant, we talk in terms of months instead of weeks. Cochlear representative coming next week. Audiologist will talk with that person about my inability to get connected to Cochlear Family website.

Hearing much better after mapping changes…S sound/words are very shrill but others seem ok…environmental sounds still loud.

Used living room infrared/loop system for TV and heard well, still using captions. Heard microwave buzzer for first time.

Summary of Week 9 Post Activation

Seem to be hearing words some better…S's are less shrill but still loud. Having roaring or rumbling type echo with words. Heard shower running while I was in kitchen…my footsteps while walking at mall.

Summary of Week 10 Post Activation

Finally got Cochlear Family website account set up after much help from Audiologist. Will work with Audiologist at visit next week to sync various accessories with processor and app.

Today….listening to computer stereo and understanding the words of the songs!!!! I have missed this so much!

Summary of Months 3 and 4 Post Activation

Saw Kelly Jan 28, no change in mapping…worked on pairing devices to processor. Saw Dr. Ebelhar Jan 30 for 3 month checkup…echo/vibrations will eventually lessen/go away…taste buds are better, metallic taste on right side, tongue still sensitive/tender, not using mouthwash or brushing tongue, using baking soda rinses several times a day…Dr. E says taste buds will eventually return to normal…Dr. E suggests that I use left hearing aid if desired, hearing is supposed to be on 2 sides, hearing moves between 2 sides of brain, aid might help implant to progress, I can choose when to use aid and when I don't want to.
Kelly, Dr. E, my husband and family feel that I am hearing better. I don't feel that as yet.

Using both aid and processor all the time now. Very interesting…some days I hear well in certain instances and some days in the same setting I don't hear as well. Don't have a clue what determines difference. Notice that first thing in AM after putting on aid and processor that my hearing takes a few minutes to really tune in.

Week 12 - using Bluetooth on phone for music streaming per Spotify and one time fairly successful for phone conversation. Started back to yoga this week…using room loop successfully. Can do combination of hearing, lip reading and captions for television use.

Understanding words on my car radio on public radio pretty well and somewhat on Darrell's radio receiving country music.

Quotes I have picked up from various places:

Patience…Persistence…Practice…Positive Attitude
"Hearing is a process, not an event." Dana M. Au.D.
"Learning to hear with the CI is a journey which is uniquely different for each recipient." Ruth F. Nucleus Recipient
"No sound is too small to be thankful for." Margo K. Nucleus Recipient
"Your hearing journey will happen one day, one week, one month, one year at a time." S.L-S Nucleus Recipient

Strangest thing…this morning I heard a soft swish swish when I put on my solid deodorant and a swish swish when I brushed on my cheek blush.

Struggling with hearing in noisy restaurants and other places with high ceilings, hard floors, people. Will request appointment with Kelly to set processor to lessen background noise and try that. Had tried it early on with not much difference in hearing ability.

Seem to be asking Darrell fewer times to repeat what he has said.

Echo, vibrations still are an issue with hearing words clearly.

February 25…saw Kelly today to do some adjusting to programs. We spent a lot of time talking about my implant and a variety of questions I have. Your best friend when you have an implant is your Audiologist!! They want to see you succeed!

Here are a few of the things that I learned today about my Cochlear brand implant:

When talking about adjusting your implant for your hearing needs, we are talking about the microphone settings, the processor configuration, the mapping of the electrodes. The microphone settings are Standard (hearing all around), Fixed (hearing on a focused area with background noises blocked, Adaptive (hearing on a focused area with background noises softened). The processor configurations are many and difficult for me to explain. The mapping involves adjusting several of the 22 electrodes to improve the level of sound heard and understood.

I leave you this month with these thoughts:

When considering an implant, be ready to commit to wearing your processor all day. Part time use will not advance your hearing objectives.
Keep a journal to help you look back at where you have been and what progress you are making.
Ask your family and friends to help you assess your hearing progress. They want to see you succeed.

Stay in touch with your Audiologist and give an accurate account of your hearing progress and issues.

Summary of 6 Months Post Activation

Next week I will be 6 months post implant activation. When getting ready to write this update, I reviewed my 3-4 month activation notes. Some things are the same. Some things are new.

The Same:

My taste buds are still effected somewhat although improved. Doesn't really keep me from enjoying eating and I don't really consider it an issue.

I hear environmental sounds really well and have pretty much from the beginning of activation. Always fun tho when I realize that I am hearing something clearly for the first time in many years.

I continue to use both my aid in left ear and my right ear implant. I have found that using both does enhance my hearing experience.

I continue to use Bluetooth for cell phone use. I have had 3 fairly successful conversations since my last journal entry. Two conversations were with my daughter who is mindful of my need for clear spoken words. One conversation was with a friend who also understands my need for clear words. Although I had one conversation a couple of months ago and did fairly well with that, I am just now ready to focus on phone rehab. I'm nowhere near ready to conduct any business by phone. I still use text and email regularly to communicate.

I continue to have echo/vibrations with all words spoken either in person or per television/radio. Overall the actual words sound fairly normal now but the reverberations make understanding more difficult. I feel that if this was not present that my hearing would be very, very much improved. I am not able to see my audiologist at this time due to Covid 19 "stay at home" restrictions. I will be eager to talk with her about this situation when able to make an appointment again. I have searched the internet with no success for any indication that other recipients are experiencing or have experienced this echo/vibration issue. I have

found a term, diplacusis echoia, which means one ear hears sound faster therefore creating an echo. Just wondering if this applies to me.

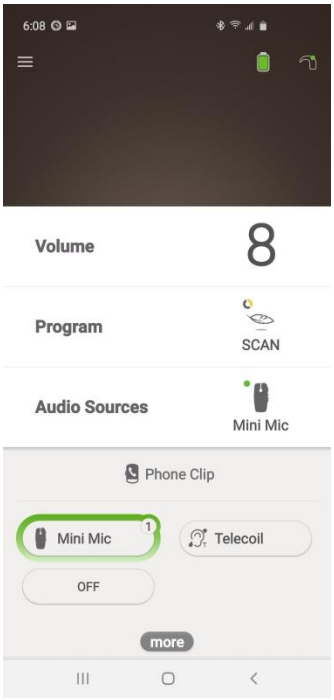
I am enjoying music so much by using streaming per my cell phone and Spotify app. The music feels more pure than before. Still have fair amount of difficulty understanding words.

The New:

I'm watching television using the Cochlear mini mic/lip reading/captions. I had an appointment with an area Cochlear representative who instructed me on the many uses of the mini mic. Thank you Colin Lyle! He also introduced me to the use of the Cochlear phone app. Up until this time, I have been using the Cochlear remote control. I have the choice now to use either one although the app has more options.

The remote control is very small and easy to carry. It controls the cochlear processor and different programs including telecoil and the volume of each.

The mini mic is very small, easy to carry. It is used for transmission of sound to the cochlear processor...used for TV viewing, group conversation, one on one conversation, etc, any setting where assistance is needed for hearing. The cord connects the mini mic to various equipment to facilitate streaming.



This picture of the nucleus smart app shows some of the settings for control of the cochlear processor.

Tried on my wig tonight for the first time since receiving my implant. Have been curious if the implant and the wig would work! And yes they do…hurray! I do have to increase my magnet strength from #2 to #3 to keep the magnet in place. Other than that, all is good. I think I have mentioned before that I can wear a ball cap or a hat with my processor/magnet without any problems. A toboggan…no…it covers the processor.

My Plans:

I want to work with my Audiologist, Kelly, as soon as the Covid 19 restrictions are lifted. I need to see if anything can be adjusted that would help decrease the echo/vibrations.

I plan to purchase a Resound hearing aid as soon as appointments are open again. The Resound aid works in coordination with the Cochlear implant. It would mean that instead of streaming mono, I would be able to stream stereo. Seems that would make a tremendous difference for mini mic uses, Bluetooth uses, and anything else that would be a streaming experience.

I will continue to talk on my cell phone with “understandable” persons until I feel brave enough to venture into other calls.
I’m looking forward to when I can return to my gym and my chair yoga classes. Will use my loop connection when I do return. Talk with you in 3 months when I should be even better at this listening world!

Summary of 9 Months Post Activation

Life is moving on despite the limitations created by the Covid 19 virus pandemic. The use of masks is essential to the effort to bring the virus under some type of control. The use of masks is a nightmare for those of us who are hearing challenged!!! Without the advantage of lip reading, communication is a struggle. I am fortunate to have my husband interpret for me when it is essential that I understand completely what is being said. That wasn’t available for me tho in May when I had a cardiac catheterization done. Because of the virus restrictions, my husband was not allowed beyond the lobby of the outpatient department. I did my proactive work by letting each and every caregiver/provider know that I am hard of hearing. I ask that they pass along the word to all who would be caring for me when I was sedated. I was allowed to leave my implant processor and my hearing aid in place. It was wonderful how everyone worked with me to make it the best situation that it could be under the circumstance.

I have my new Resound hearing aid now and am extremely happy to be hearing in stereo when using Bluetooth cell phone, streaming music and NPR from my phone, and using the loop system at my exercise class. I still stream mono when using my mini mic for television viewing but the hearing aid brings in sound to my left ear. I learned what hearing with one equipped ear is like when I was 2 weeks without an aid waiting for my Resound to arrive. Grateful to have both ears doing their magic now!!

I spent an hour plus with my audiologist working on finding a solution for the echo/vibration that was hindering my implant hearing. She went through each electrode searching for one that might be creating the issue. Sure enough, she found which one it was, turned it off and bingo, the echo/vibration was gone.

I'm having good success with using the cell phone now! That is a big breakthrough for me!! With my Resound aid, I hear Bluetooth in stereo. Makes all the difference in the world.

I'm using my cell phone Nucleus Smart app exclusively now to control the various times I need to fine tune my implant settings.

Something that has been helpful for me is finding a couple of Facebook groups who are geared for those of us with cochlear implants. Those groups are Cochlear Implant Users and Cochlear Implant Unbiased Experiences. Even though many of the issues may not apply to me, it's just helpful to know there are more of "me" out there!!!

I will go for now. I'll be back in November when it will be one year since my implant activation and the beginning of this wonderful new life journey!!! Take care all of you and stay safe!

Summary of 1 Year Post Activation

2020 is and continues to be a trial in many ways. With that said, 2020 has been good for me and my hearing progress. This will be my final notes for my blog. It has been wonderful to have you travel along with me this year with my ups and downs of my cochlear implant journey. I will continue to grow in my hearing abilities and to be available for a chat. Feel free to touch base with me through our website, hearinglosskentucky.org.

The last 3 months have been what I consider a "polishing" of abilities that I had been developing. By that I mean that sounds and situations have begun to improve in subtle ways.

I now can successfully make not only personal cell phone calls but also business calls. I accomplish this with my Resound hearing aid, Cochlear processor and Bluetooth cell phone. This gives me "stereo" sound. I do not use a land line.

I view television programs using my Resound hearing aid and Cochlear processor synced with my Cochlear mini mic and the respective cell phone apps. Some programs I am able to understand well using both the mini mic connections and captioning. Some programs I understand well using only the mini mic/cell phone apps connection.

I listen to music on my cell phone per Bluetooth connection to both my hearing aid and my Cochlear processor. I am thrilled to be able to enjoy music again!! I do hear music on the car radio but it is somewhat distorted. I have not been to a live music show as yet.

I continue to use the loop system at my exercise facility. My hearing aid has now been synced to loop capability so that I'm hearing with both my hearing aid and my processor. Again, stereo sound!!!

I had a new mapping done in September and that has served me well. No adjustments needed to be done at my one year checkup. Mapping is the adjustment of sound settings for the processor. Adjustments are made as hearing changes as based on user feedback.

A very short sample of new sounds:

Swishing of husband's tooth brush when brushing;
Squeaky floor in front of washer;
Misting sound from iron;
Water filling in the washer;
And many more!

Experiences that are still frustrating:
Taste buds still not back to normal;
Understanding in large groups;
Understanding where ceilings are high, floors are hard, room is large;
Understanding someone if they speak fast;
Understanding servers, clerks;
Mask use during Covid.

I've been thinking about what I might say to you if you are thinking about having a cochlear implant. Keep in mind that I am coming from the perspective of someone who began developing hearing loss in her late 40's to early 50's. There are many hearing loss scenarios. I can only speak from my experience.

The following are a few of the things that I think might be helpful:

Think about why you might want a cochlear implant and write down those reasons.
Think about what you might fear from having a cochlear implant done and write down those things.
Research information from reliable sources.
Read information from all three of the cochlear companies.
Locate facilities close to you that perform cochlear implants.
Communicate with cochlear implant recipients.
Talk with your family about the cochlear implant and what it might mean for all of you.
When ready to take the next step, make an appointment with a facility close to you to discuss your questions and concerns with surgeon and audiologist and what they have to offer. Take someone with you to help understand what is being said.
Keep in mind that your comfort with the providers, surgeon/audiologist/and facility, is essential to your success.

My last thoughts:

It is important to have someone who can be available to help you for a few days after surgery.
I feel that having a facility, surgeon and audiologist near you is an asset.
Do not expect instant hearing improvement. It is a journey.
Keep a journal. Often you will not realize improvement until you see where you have been.
Learn how to utilize the accessories that go along with your implant.
Ask for help when you are struggling.
Most of all relax and take it one day at a time!

Thank you for being with me this year!! I wish you the best!

Donna

2 years post implantation and activation!

Hi Everybody! I thought that I might return for a little chat with all of you about where I am now with my cochlear implant.

I remain pleased with my implant decision. Yes, I am deaf in my implanted ear without my processor. Yes, I hear in my implanted ear with the processor.

These are the things that I am enjoying with my implant:

Music! Car radio, TV, and Bluetooth phone app. I have full comprehension of instrumentals and am getting better at understanding words. I have not attended an in person event as yet due to covid precautions.

Television! Great using the mini mic accessory/phone app in combination with captioning. Just purchased a new TV that has 5 speakers instead of 2 in the old one and I am able to understand dialogue without using the mini mic. I am able to combine hearing words, lip reading and captioning successfully.

Group conversations in a fairly quiet atmosphere! Friends and family tell me that they can tell that I am hearing better. I feel more engaged in groups and less withdrawn!! A real win for me!!!!!

Phone use! Ah yes, this is a biggie! With my processor and Resound aid, I am able to successfully use my cell phone by way of Bluetooth. I now can conduct business calls and personal calls.

Environmental sounds! I find myself asking, "what is that noise?" Finding new sounds in my world!

These are the things that I am still working on:

Group conversations! Still having trouble once the gathering becomes noisy. I'm learning how to adjust my phone app settings to assist some with hearing in these situations. Still not super successful.

Persons with masks! I'm doing somewhat better with this but still a long way from successful. I find that if I tell the speaker that I have hearing loss, that they look directly at me and speak more clearly. Even tho I can't see their lips, this does help with understanding.
Vehicle conversation or living room conversation with my husband! I am able to understand him very well if we mute the car radio or the room television for the conversation.

Servers and retail clerks! I am doing well with these situations as long as there are no masks involved.

Settings with high ceilings, hard floors, background noises, voices with foreign accents! Still a struggle.

Other things of possible interest:

I maintain regularly scheduled mapping visits with my audiologist and find the adjustments helpful. I have annual evaluation with my hearing aid provider.

I stay connected with other cochlear recipients through a Facebook support group, Cochlear support systems, and hearinglosskentucky.org Cochlear Implant Info section.

I devote sometime each day to wearing only my processor. I do hear more completely with both my Resound hearing aid and processor on. Voices with my processor only still sound somewhat cartoonish. Aid helps to normalize voices.

I continue to have an occasional taste difference but nothing significant. I have no vertigo issues due to implant. I do have history of menierre's and positional vertigo. Neither has been worsened by the implant. I can wear hats and caps without issue.

My two year audio screening in quiet booth for single word comprehension and sentence recognition:

With aid and implant processor….78% and 80 %
With implant processor only…79% and 77%
Implant processor only in noise…44%....did not test processor and aid in noise

Until next year!!!!