

1) My Surgery Experience

I had my surgery at Lenox Hill

Hospital in NYC on Thursday, Sept. 28, 2000. Dr. Darius Kohan was my surgeon. My parents and I showed up at the hospital at 9:30 AM. At noon, a nurse asked me to come into a room but she wouldn't let my mom in and we didn't understand why. At first I thought I didn't even get to say goodbye but then they explained that it was a room where I would be changing into the hospital gown and then I would be asked a lot of questions several times by different people. After a while, they let my parents in and my grandmother (90!) was there too. Then they asked us all to wait in another waiting room because they needed the room for someone else.

Finally, a man came and checked my i.d.

bracelet to make sure it was me (wouldn't want them to take my gall bladder by mistake!), and he wheeled me to a pre-op room where a lot of other people were on gurneys waiting for their operations. The anesthesiologist, a surgeon (in training?), Dr. Kohan, a couple of nurses, the surgical resident, and someone from my audiologist's office came to visit and asked all the same questions again. About an hour later, they wheeled me on the gurney to the operating room. I found out later, that my parents were already freaking out by this point because none of us realized I would be waiting so long.

When I got to the operating room, I had to remove the outer gown and just leave on the one where my big tush ;-)
sticks out the back, and I had to walk into the operating room and jump up on the table myself! They didn't give me any pre-op drugs but I think I appreciated that. I sat up on that operating table and watched everyone as they came in with their clean arms and started putting all the operating stuff out on the tables. I got a good look at all the machines in the room. I just wish I could've asked more questions about them! The anesthesiologist started teaching the surgeon in training about how to find a good vein for the IV. Fortunately, I have several good veins popping out all over my arms. Then I could feel the first rush of drugs go through me and they strapped both my arms firmly down against my hips. The surgeon and the anesthesiologist waited over me and said goodbye, see ya' later, don't worry about anything! I just looked at the surgeon and said good luck and then I fell asleep. I woke up on the way out of the operating room with that big jock-like cup over my ear but I couldn't stay awake. The pain meds did hardly anything for me but I was ok as long as long as I was sleeping. After about an hour in the recovery room (the nurse yelled at my mom because my mom wanted to come in and the nurse wouldn't let her), I was wheeled to my room and I stayed overnight. Somehow I got a private room! I went home on Friday and stayed at my parent's house until my post-op appointment with Dr. Kohan on Monday. My incision

(staples) healed very well and although the surgeon said not to wash my hair for at least one week, there was no way I was going to wait that long. I had my Mom hold a towel over my ear and she washed my hair as I hung my head over the sink. It took about 10 days for me to really feel like myself again because the antibiotics I was on were very strong and made me feel dizzy and nauseous. Towards the end of the course of the medication I realized that I felt better if I took the dose just before bedtime.

2) Why I chose the Nucleus 24

I am a post-lingually hard of

hearing woman (almost 39 at the time I wrote this) with what is known as a ski slope hearing loss. My loss was first found in the 6th grade during a routine hearing test in school. I have pretty good hearing in the low frequencies and it just drops off to profound deafness in the higher frequencies. My last pre-implant audiogram taken June, 2000 shows the following (average) results for both ears:

15 dB @ 250 Hz
45 dB @ 500 Hz

85 dB @ 750 Hz

100+ db @ 1000 Hz and higher.

My speech is perfect and I have been able to get along ok in life with lipreading. I decided to go for an implant because I wanted my life to be better and I was at the point where I felt my teaching abilities were suffering. I believe that I was on the last leg of hearing and that I would be losing it sooner rather than later. I already had very little social life but the last straw was that it was affecting my teaching job. I was implanted with

Cochlear's Nucleus 24 Contour. I spent a long time trying to evaluate the implants, I asked a lot of people a lot of questions, and read all the literature from two companies. I did not research the Med-El because I (and my surgeon) felt the company was not established enough in the United States at that time.

The task of having to choose between brands of CI, knowing that you can NEVER really know which is better and certainly can NEVER switch, can seem monumental!! But I hope to convince you to please not let this decision become a huge factor for you. ALWAYS keep in mind that whichever brand you choose will work for you. Now, fully acknowledging and accepting this, here is what I did. I looked at both the Clarion and the Nucleus and I had a gut reaction to the Nucleus. I liked that the implant was much thinner inside my head and did not have a ceramic casing which, G-d forbid, seemed like it could shatter if you had a real bad bump to your head. However, this is so very rare. Beyond this gut reaction, I have to admit that the rest of my research was probably to justify what I felt. I liked that since I am only 39 years old, if I ever needed an MRI it was still possible with the Nucleus. I liked that Cochlear Corporation has been around longer than Advanced Bionics. I

liked that there were more electrodes in the Nucleus and felt that I would benefit from it's greater flexibility for programming. I especially liked that the Nucleus already has the BTE out and if I am going to buy now, I might as well buy what exists rather than what was promised for quite some time. I liked that more people around the world were implanted with the Nucleus. I also tried to read up on how the ear works and the physics of sound, but I didn't understand as much as I had hoped. But I took a chance and wrote to someone who is the head of audiology at some big university and she was kind enough to write back and confirm my choice of 22 electrodes as having more flexibility for hearing. I subscribed to the York forum and the Nucleus forum and did nothing but lurk, really. But what I noticed was that I read about more complaints on the York forum which seems to have more Clarion users. I also noticed that as I met/e-mailed more and more CI people, I tended to identify with the Nucleus users as people. The Clarion people on the York Forum were much more politically bent and always spoke to me with a hard sell attitude (which I dislike very much) and the Nucleus people were "live and let live" types. Does that seem like a stupid reason? I don't know, but remember, whatever works for you is valid for you. So in conclusion, go with your gut!! Look at the devices and the extra options they offer. Read the forums, be happy, and look forward to hearing.

3) Hook-Up Days 10/26 - 27/2000

I was very nervous in the waiting room but finally I (and my Dad) got called into the audie's (Amy Popp #1!) office. First she hooked the CI up to the computer, and to my head, and we did the NRT test for the electrodes and then the threshold test. I had to count how many beeps I heard as we went through all 22 electrodes. My tinnitus seemed loud but I worked hard to try to hear the beeps through all my head noise. Then we did the comfort levels where I had to tell her to stop when the beeps were loud but still comfortable. Finally, we ran through all the electrodes first 5 at a time and then all together to check whether they were all at about the same loudness. Ok, everything was fine!

Then the audie took me off the computer and let the sounds of the environment come through. I still had the hearing aid on in my other (left) ear so I could understand everything with that ear. But I could hear a lot of high pitched sounds coming through the CI ear. I didn't like it at all. I took the transmitter off of my head twice because I did NOT like it!! Then I took the hearing aid off to see what it was like. And I'm still listening to my audie and hearing these high pitched sounds in the implanted ear but not much in the way of speech in that ear. I could still understand with the unaided ear and plenty of lipreading. Just a minute later I decided to close my left ear with my finger and listen with only the CI. All the speech

sounds disappeared and all that was left was what sounded like the hearing test we had just gone through with high pitched squeals and squeaks and lots of beeping. And there was plenty of white noise and what seemed like tinnitus in the background. I WAS DEVASTATED!!! This was not sound!! I put my head into my hands and just started to cry. I could've cried a lot longer than I did. After all the reading I did about what everyone else's experience was like, it could not have possibly prepared me for what it was like to experience sounds with the CI. I remember someone said it was like Munchkins on helium. That would've been wonderful!! These sounds were not human to me and I had never felt more "defective" in my life.

Ok, I stopped crying and I kept listening to my audie and my Dad asked some questions too. And as they were talking, my audie was slowly raising the volume on the CI from 2 to 7. She said this was an improvement already. We finished up by her explaining to me all the wires and the Nucleus case and how to use the processor and all the other details. Then she sent us out into the street for 10 minutes. We came back up and finished for the day. She was surprised when I told her that I had planned to go to the League for the CI meeting but I was determined to see some people there who had had their surgery and hook-ups around the same time as me. I went out to dinner with them afterwards too! I am grateful that my head didn't feel like exploding. The next day I had my Mom with me. We went through the same tests for the electrodes, and then the threshold and and comfort levels. I couldn't help but cry again because the reality of these sounds is a hard bite!! But I asked a lot of questions because I like to learn and be informed. And I got 3 more programs that I have to switch every three days or so to see which I like better. I also don't know which they are yet, and frankly I have no interest in knowing. With all this emotional upheaval I figure some things are best learned on a need-to-know basis. Mom and I spent the rest of the day in the city and then took the train back to Brooklyn.

I woke up the next morning finally feeling rested and it felt like the last two days were just a dream. Everyone says it'll get better and I had to believe that. But this has to be the hardest thing that has ever happened to me. I guess I should be thankful in a way that nothing so demanding has ever happened before. I bought Curious George on tape to learn how to hear all over again. I looked for the small improvements every day because my goal is to be able to have conversation without lipreading. I may be a Yankee fan but the Mets fans have one thing right: "YA GOTTA BELIEVE!!!"

4) 2 Weeks Post Hook-up Appointment

I know that I didn't have the greatest experience at hook-up. But today I went back to my audie and we have

some good news!!!

After hook-up the difference between my T and C levels went from 8 to 13 decibels. Now they range from 15 to 42 decibels. The greater range is in the lower frequencies because I had heard them much longer than the higher frequencies before I received the CI.

I am now able to hear my telephone ring from another room if the house isn't too noisy, I can hear my bird scream (he may get himself into trouble!), I can hear a car alarm from 5 floors up, and I heard a cell phone ring for the first time ever. The CI noises definitely do sound like speech even when I don't know who is talking. I can tell that someone next to me is talking even over the din of the subway! But I still don't have comprehension in the CI ear without lipreading. Sometimes, I think I can tell the difference between male and female voices, but I'm not always sure. I borrowed a piano keyboard from a friend and I can make out the difference between adjacent white keys just barely. But I think that is a good thing for now. So, putting it all together, I have definitely made progress in the last 11 days or so!! :o)))) I am just going to try to dwell on the good stuff. BABY STEPS.

As far as the appointment went, checked the electrodes first, did T levels, then C levels. It turns out that my 4 programs were Speak, Speak ,Ace, Ace. I liked Ace better but now I am back on Speak and every program has been juiced up. I want to be able to switch as I need to and be flexible with the strategies... eventually, of course.

5) One Month Mapping

I am so pleased and proud to be able to share my one month anniversary with everyone. It is especially wonderful to be able to do this on Thanksgiving. Even though the hook-up days were emotionally traumatic, I've come a long way by leaps and bounds! My comfort levels have increased very significantly. I scored around 40% on the test listening to individual words, and about 85% on the sentences test. I can hear my telephone ring as well as other people's cell phones and beepers (not that I want to! LOL). I even heard my phone ring while I was in front of a sink with the water running! I can understand a lot of what the conductor on the subway says. Those of you who ride NYC trains know that this can be an almost impossible task for even the normal hearing. I understand most of the news/weather/traffic reports on AM radio. I understand much more of what my students in class say without having to run around the room to be close to them. Male voices are starting to sound a lot lower than female voices. I was able to understand a little bit more than before while I was on a date in a very noisy restaurant. My very good friend Rob told me that he has had to repeat what he says a lot less and that I am

less frustrated (and frustrating). I was sitting behind my Dad who was driving, and I heard him ask my Mom something and I couldn't lip read him at all! So I am getting much better at speech comprehension without visual cues. I still feel uncomfortable even trying to do that sometimes because I've had to rely on lipreading for most of my life so it's kind of an emotional task too. I understand some TV without captions but in general I still need them. I haven't bothered with the telephone with my implanted ear because the phone is my greatest hurdle. I'm just going to wait until I'm good and ready and not rush it. Music definitely makes some sense. I can hear the rhythm and can tell when there is someone singing. I can't make out the words though. Soft jazz and ballad-type singing is the easiest. Some music, like harder rock and some disco, is still just noise because there is too much there to sort out. The sounds of the CI are still very mechanical and not natural but now that's ok because of increasingly better comprehension!!!

None of this would have been nearly as good as it is if not for my dear friends on the Nucleus forum, my fabulous audiologist Amy, as well as close friends and family, who have been there every step of the way with their patience, humor, encouragement, and wealth of information. This is truly a time for thanks!!

6) 3 Month Mapping

I made significant gains on my comfort levels. My sentence recognition scores were 99% in quiet and 98% in noise. My single word recognition scores were 58%, up from 32% last time! I hear the birds chirping every morning on my way to work. I understand some TV without captions although I still prefer to keep them on. I went to 2 movies that I understood very well (Family Man and Chocolat). I heard someone call my name across a crowded, very noisy room, and I can finally have those casual, quick conversations with strangers without having to say "what?" seventeen times!! I went to a bar with a friend and understood her through all the loud music. At least now I can say that I don't like going to bars, but not because I can't hear in them. I have begun to use the phone without the patchcord; I just hold it up to the microphone. I use it with more familiar people and when I am making the call. Sometimes when someone calls whom I don't know I will attempt to struggle with my unimplanted ear. When I got home from all the testing, I was happy to find a jury duty summons in the mail. How's that for a final induction into the hearing world?! I feel much more effective and confident in my classroom because I have more patience and better understanding of what the kids are saying to me. Although that has only confirmed what I suspected before...they still don't make any sense!!!

LOL

I am deliriously happy with having made the

decision to get the CI... especially the Nucleus (yes, I am speaking for myself!) and I continue to look forward to new mappings with the best audiologist (Amy Popp) anywhere.

7) 6 Month Mapping

I had my 6 month testing done this past week (actually, I am still in my 5th month). Sentence scores in quiet and noise were almost 100%. I only missed one word out of 204. My single word score was 78% up from 58% at the 3 month mark. I am very happy about all of this!!!

At this point I am now realizing that the honeymoon is over. What I mean is, it was very exciting to finally be able to hear all those high frequency sounds that I hadn't heard in so many years, I am finally able to understand speech much of the time without lipreading, I am finally able to enjoy going to movies, etc, etc. But I feel this is where the real work comes in for me now. I remember what it is like to have normal hearing and this is not normal by any standards. I have had a hard time trying to communicate with my audie (NOT in any way because of her) what it is I want from a mapping because I don't know what I can expect to have over the long run. Low sounds are sometimes "gargly" sounding and high sounds are sometimes "buzzy" (much of this depends on the speaker) and yet I still hear 100% according to test scores. And to ask others what they hear is really a futile effort since hearing, and our descriptions of what we hear, are so subjective. I am also working on trying to figure out which type of program works better in different listening situations. And I am the lazy type - I'd rather just leave the thing on one program and be done with it! ;-)

I am not complaining about the CI at all...I

LOVE IT!!! I am grateful every time I hear a bird in the morning or a person speaking, and I am especially grateful for the incredible lack of stress I used have due to being HOH. I just wanted to share where I am at the moment, the ups and the downs.

8) Update - 20 Months Hooked Up

I still love my CI and sometimes have to remind myself that I am still a hearing disabled person. Even though I can hear so much, there are still limitations. But I try to participate in life as fully as I can. I go to movies, I use the phone without reservation, I can have a conversation without having to focus on the person's lips, I am happier and less stressed and finally becoming more the person I have always wanted to be. I contemplated sequential bilateral surgery but I am not ready to give up the residual hearing in my left ear as I can still wake up with a clock radio in the morning. Deborah Lee at MEETH in NYC is now my audiologist and she works tirelessly to give me maps that make me happy. I have been so blessed to have had these 2 great women as my

audies so far.

I recently had some very good news! It would seem that my auditory nerve may have improved in that it now takes a lot less electrical stimulation for me to hear, with full comprehension. When my C levels were higher, I had some facial stimulation from some of the higher pitched electrodes. But with lower C levels and no loss in clarity, I have no more worries about facial stimulation and also get much longer battery life. Right now my biggest challenge is to find a mapping that sounds as natural as possible; I go for mappings more frequently than before. I also have my long awaited 3G and it is awesome! It only holds 2 programs so it is more time consuming to find the right program on it but I am confident that it will happen. The 3G is very lightweight even with the 3 hearing aid batteries and the telecoil for the phone is my favorite feature. Although ADRO on the BWP is best, the telecoil works really well in the movies as well.

I am now a volunteer for the Cochlear company and couldn't be more pleased or proud. I have been advocating for the hearing impaired and for CI's since I was hooked up so this was the next natural step for me. I receive no money for what I do; I do it because I enjoy it. For me there is no greater joy than being able to give back.

9) Two Year Anniversary

Even after 2 years it continues to be a journey of gifts and miracles. I've never had so many friends and my confidence and self-esteem have soared. I was sitting in the subway one day and saw an advertisement for one of those walks to raise money for breast cancer. This wasn't just a 2 hour thing in Central Park, but a 3 Day/60 mile walk and you had to meet a minimum fundraising amount. Never before would I have considered doing this because I wouldn't have dreamed of putting myself in the middle of a group of strangers knowing I wouldn't be able to hear. I decided to go for it. I raised much more money than was required and made more friends in the process. This to me is the best example of the power of having your hearing back. There are doors of opportunity that open for us each and every day. Whereas before I had to say no, now I can choose to say yes and enrich my life. It is not the CI itself that changes us, but the willingness and ability to take full advantage of what is offered us.

Speech through a CI still does not sound normal to me. There is some normalcy but it is wrapped in a CI resonance that sounds very much like a microphone. I accept this totally. I had my 2 year CNC testing just last week. I scored 92% on single words and 96% on phonemes. I was tested using my 3G so in essence this little processor passed with flying colors as well!

10) A Typical Day with a CI

I wake up and get ready for work. I am still glad to be able to wake up using my residual hearing. I put on my CI after I shower, dry my hair, and put on my perfume. I walk the short distance to work and even now my heart still swells with the sounds of the different birds in the trees. I spend quiet time in my classroom to prepare for the day.

My friends come to work and we hang out and gossip a bit. (Ok, a lot!) The teacher's Lounge gets VERY noisy so I either use the autosensitivity setting or I turn down the sensitivity. I still need to read lips in noise. Then the kids come in and I begin another day of teaching junior high math. Most of the time the kids understand that it can be challenging for me to hear them if others are talking at the same time. This year is more difficult than most and the kids need constant reminding of my limitations. We are all working hard on this. During my prep period, I either consult with other teachers or make phone calls to the homes of misbehaving students. I switch on the t-coil on my 3G and no matter how much noise is around me, I can hear on the phone.

After work, I run errands or watch a little TV. I still like to use captions although I can often do without them. I make phone calls to friends and family and other business. If I have to drive somewhere I enjoy listening to music (better with the windows closed, though).

On the weekends, I may see a movie (I choose what I think I will understand best and must turn down the sensitivity), go out with friends (yes, even to noisy clubs!), or stay at home and not put the CI on for the whole day - it's my choice.

I think I am ready to end this journal. I feel I am at a point where although I know the CI moments will come, they will be fewer and further apart. I wrote this journal with the hopes that others will find some benefit from it as well as to keep a record of how far I have come from profound hearing loss to finally being able to have a life!!

With thanks,
Leslie Carol Berg