

MARDIE's CI Progress (1996-1999)

(Mardie Younglof retains the intellectual rights to her story. Its presence does not place it in the public domain. Please respect her rights.)

This article was first posted online at Listen-Up Web which is now defunct. We thank Mardie for granting permission to describe her post-CI progress. In my opinion, given the passage of time since 1996 this ranks among the best personal accounts of post-CI progress.

It is important to note that Mardie Younglof is prelingually profoundly hearing impaired. She was the first client of Helen Beebe in the 40s (<http://www.agbell.org/Document.aspx?id=653>). When she was a toddler, she wore a body type hearing aid which weighed about two pounds. As such she had an auditory pathway built in even in the long years of hearing aid usage – which more than likely maintained a semblance of P1-N1 integrity that is found in children who received sufficient stimulation in the critical early years.

The Surgery

The surgery took place on Nov. 20, 1996 at Johns Hopkins by Dr. Niparko. The operation itself lasted 90 minutes, but I spent 4 hours in the recovery room because I was quite sick from the anesthesia as well as overwhelmingly dizzy.

Dr. Niparko and Ginger Grant, an audiologist, did a quick audiogram of me shortly after I awakened. Even though I was nauseated, dizzy, and groggy, I still managed to test in the 35-50 dB range and was able to distinguish between low and high frequency sounds. I could tell they were delighted by the responses I gave, and we (my husband and I) too were glad to know that at least this fancy new gadget I've got embedded in my head is going to work.

There was a huge plastic cup attached over the ear area, with a Velcro band around my head to keep it in place. This cup applied pressure to the "wound" but sure was uncomfortable to live with for the next 3 days. My poor right ear got flattened out from nonstop sleeping on that side!

At JH, CI surgery is done on an outpatient basis, so I was sent home that evening. During the night I could feel seepage of blood and had to drape a towel around my neck then and the next night as well. JH assured us it was normal, but it was a little alarming to me, because I have tended to hemorrhage during surgery in the past. There was little swelling of the wound area; instead, the fluid migrated to the left side of my face (the surgery was on the left ear), turning me into a bedraggled sorry-looking chipmunk! That swelling is now completely gone.

The biggest problem, by far, that I have experienced is the dizziness. The first 2 days were the worst. Every move made the world go upside down. Finally the dizziness shut down my stomach and I couldn't hold anything down for 3 days, losing 10 pounds in the process. We went back to JH two days ago, where they quickly identified the problem as vestibular imbalance caused by the surgery and prescribed medication to settle my stomach. I am now again eating normally but in small portions. The imbalance, they say, will gradually go away, hopefully by next Wed. (this is Friday). In the meantime I cannot drive a

car and thus have to stay home from work all of next week (my poor boss is going to moan and groan at this news). My family and friends have been just wonderful, and I am truly grateful for all their support, especially my saintly husband!! I was not able to be left alone from the night I came home from surgery until now.

I didn't have much head pain, but at night sometimes there would be sharp twinges around my ear. I took no pain medication at all.

Based on my experience, I offer the following suggestions for those of you contemplating surgery or are scheduled for it: First, make sure you have someone who will be able to take care of you if you experience complications. (I have no idea how common my problem with dizziness was; do know a few of you have had it, but please email me and tell me if you had the same degree of difficulty I did, and what you did to recover.)

Second, you should clear the books of engagements for the next couple of weeks to allow yourself time to recuperate. You aren't going to feel very pretty for a while! (Bill's recommendation of hats is a good one, haha, also scarves or hair bands) Baby yourself; this time is for you. It is not the time for running around attending meetings or wearing yourself out.

The people at JH were wonderful to me, and I have no complaints about the care they administered. Each staffer was totally professional and kind and made certain to look right at me and talked normally and I was able to lipread everyone.

Hook Up

Hook up went smoothly, but my audiologist got quite a surprise when she tried a CA program on me at the second appointment the following day. I gave a neutral response to it, not indicating a strong reaction of "yuk" experienced by most CI users. The sound was quite different from the CIS programs, but not repulsive enough for me to reject it outright. Consequently she placed a CA program in one of the slots on my Clarion processor, with the other two having CIS programs.

Speech initially sounded flat, very "quacky," which some of you have talked about, and I now know just what you mean. At the end of the first day, my husband's voice was just beginning to sound a bit "fuller." I picked up all kinds of sounds I had never heard before, such as the clicking of the turn signaler in our car, the scrape of a fork across a plate, a plastic bottle falling on the floor 20 ft. away, coughing, throat clearing, etc. It was overwhelming, and after dinner that first night my head was yelling, "Mardie, enough!!! Lemme rest!!!" And I took off my new gadget for the duration of the evening, relishing the availability of captioned television for relaxation in our hotel room.

The next day my audiologist found my parameters to be quite different from those set the previous day, a good sign. With the new CIS programs (similar but one more strong than the other), speech is slowly sounding fuller, less quacky. I really don't know how much the vertigo I still have and the tinnitus are affecting what I'm hearing. We found that I can't hear our doorbell, which is very soft and muted; this means, I am sure, some adjustments at my next appointment on Dec. 27 will be in order. Voices still

sound like they are vibrating; it's hard to describe what I mean. In other words, voices don't yet sound smooth.

Turning on the car radio and with feedback from my husband, I was able to distinguish between music and speech, but could not understand any words being spoken. Singing was just a racket.

It is obvious I will have the power and volume I need to be able to understand speech without that eternal feedback problem I had with my hearing aid.

All these strange sounds I am now suddenly hearing are just overwhelming, and I tire very easily as my brain tries to digest it all. Am just letting sounds "fall" into my ear continuously, knowing that my brain will eventually sort it all out. How long that will take is anyone's guess. The feeling I have had since hook-up is like a little kid learning to walk and seeing there is a whole world for him/her to explore!!! It is such a great feeling, and I am eager to just hear and listen all day long.

One Week After Hook Up

My third mapping took place last Friday. The audiologist first ran an audiogram with the program I'd chosen as the preferred one, and we were very surprised that in the speech range I came in at 25 dB, which then dipped to 50 dB in the high frequency area. She subsequently adjusted for that and moved all parameters upward to reflect my increasing ability to tolerate the volume. I was given 3 new programs, all CIS, to play with for the next few weeks.

The difference between these new programs is so subtle that I'm having a hard time choosing a favorite. (The audiologist had told us that from now on we would be fine-tuning my gadget.) Speech is a little clearer now, with less "echoing" and more naturalness to what I'm hearing.

I can now distinctly hear consonants for the first time in my life. My husband is trying to break his habit of raising his voice to me and talking more slowly; instead, he is now trying to talk to me as he would a normal hearing person. I can easily understand him in this new speech mode, to his great delight. Lipreading is much easier now, less of a strain on me. My audiologist stressed to me that people around me should talk to me in normal tones.

In a restaurant I could clearly hear people talking at the table behind ours. It was easy to tell if they (the men particularly) were talking or laughing. I could also hear the clinking of dishes being stacked at another table near us, which interfered with my ability to hear the conversation at our table! Car horns are clear. I can hear the numbers being punched on our microwave oven, and its bell go off when done cooking. Footsteps are another new discovery, as people sound differently when they walk.

We watched a movie on TV we had seen several years earlier, and what a difference my gadget made!! The dialogue (nuances of speech) and audio effects were wonderful (we also had the captions going; am not yet ready to give them up).

Music is another new experience. Having been deaf all my life and unable to tolerate the loudness of music for much of that time, I had never been able to appreciate music. I could only watch my family

and hearing friends laugh and weep over music, in puzzlement. But now things are changing! I have a walkman with a Clarion patch cord and some tapes I swiped from my son's old room. Mozart was fabulous, and so was Schubert. The country western music my husband played on the car radio today was nice, fun to listen to, but the higher notes of Mozart were much more to my taste! (Someone commented on Beyond Hearing that CI users tend to prefer the higher notes while hearing aid users prefer lower notes, an interesting observation.)

Our New Year has started on the right "note" ;-D and is going to be the year of sound and new discoveries for me and for those of you going through the same wonderful, challenging experience! Happy New Year to all of you!

One Month

I received my fourth mapping--the one-month session--at Johns Hopkins last Friday. As I suspected, there was a big change in my response to sound since the last session (on Dec. 27). My audiologist found there was an unusually wide gap between the point at which I heard the sound and the point where the sound reached the limit of my tolerance; this was particularly evident at the highest frequency. This showed that I had greatly developed my ability to tolerate sound. She was pleased by this discovery, feeling it indicates rapid progress on my part, and said most people don't show this great a change in their maps.

I now have three new programs to "play" with, based on the change in my map. The difference in sound is remarkable. I had been pleased by the sounds I was hearing after the Dec. 27 map, but this time I am just stunned by the improvement in my ability to hear AND to understand! The first test of this new map was our door chime. I had never been able to hear that door chime well, not even with the Dec. 27 map, but now, finally, that last sound barrier has come down! All entry doors squeak unbelievably loudly, so we will need to get out the graphite!

I can also hear the furnace and water gurgling through the pipes. I heard a sound in one of our cars, which Bob (hard of hearing) had not heard, and he later confirmed it with a hearing person.

Aided by lipreading and with the captions turned off, I can easily understand with no straining about 2/3 to 3/4 of what they say on TV. I also understand a bit of what is said with the speaker invisible. We are still using the captions for the most part but there will come a day when I'm going to have to wean myself from dependence on them, and Bob will use an FM system (Easy Listener).

A friend loaned me a phone amplifier called Phonemate, which, after making a few phone calls, I found works as well as the Clarion telephone adapter. I am not yet able to make voice calls independently of assistance, but I can understand words and occasional sentences. I now can understand everything when I dial a time/temperature line, and I also dial a job line solely for practice. I talk on the phone a few times a week with cooperative (!) family members and friends, just simple, brief conversations.

Commuting to and from work, I listen to the car radio. After getting fed up with hearing country western, last week I watched to 630 on a regular basis to focus on talking rather than music. This is

great practice for me. I can tell when a traffic report is being given, understand the weather forecast, identify occasional words and phrases, phone numbers, numbers in general, including street routes. Some speakers sound wonderful, others I'd like to muzzle! As the days pass, I am picking up more and more on the radio. It has become a daily game with me to see how much I can understand, and because of the fun I'm having doing this I now love my commute!!

At home we practice "sentences" a few times a week (no longer than 20 min.) and have noticed a big improvement with this new map. I also pick up words people say when not looking at them. In fact, yesterday, while at my computer I was playing my walkman (pop music) and suddenly realized I was understanding a few words when they were talking between songs, even though my attention was focused on the computer. The same thing with the TV: while doing something else, I recognize a few words here and there.

Music continues to be wonderful, but I am focusing on just instrumental music at this early stage, and like music with a lot of high notes and lively movement. Mozart is still my favorite, but I also listen to 104.1, which is pop and dance tunes.

I got from the library some unabridged audio books and texts to match, to read and listen to each nite. I am hoping that by doing this (as well as everything else I have talked about in this update) my brain will be patterned to understand what it is hearing. My goal is to understand audio alone.

Nancy recently commented on B-H (Beyond Hearing mailing list) that people now having to learn to communicate with her more normally. That is what I am constantly reminding people to do. My husband made the switch just about overnight but others need to be prodded into remembering to talk to me like a hearing person. My audiologist told me she hears a lot of complaints from CI users that they want people to talk to them rather than sign. Hearing people are now much, much easier for me to understand than they were in the hearing aid days. Another nice side effect of my "gadget" is that (people tell me) my speech has improved in crispness and clarity.

The uninitiated must be thinking by now, "What a lot of work!" Yes, but a lot of fun, too. It is such a challenge, and so thrilling to see every little bit of improvement and to discover new sounds I never heard before. My family has been very supportive and vitally involved in this "project," for which I will be eternally grateful. And I am just amazed by, and appreciate, the interest of so many people in how I progress. This gadget of mine is doing exactly what I wanted it to do: open up doors and opportunities!

Three Months

Since the late January mapping at Johns Hopkins, we had to make an "emergency" visit in late Feb. because I was experiencing serious problems with high- frequency sounds. The rattling of grocery bags and clatter of dinner dishes were driving me insane; I'd have to turn off my speech processor in order to put groceries away and do the dishes. At work, the screech of the fax machine became an piercing siren; even the pinging of the office microwave machine was anathema to me. My audiologist made some adjustments and sent me home with new programs. We returned last Friday for my regular three-month checkup.

At my request (at Hopkins they now run these tests at the 6-month appt.), she tested me on single-syllable words and sentences. My son was with me in the sound booth, sitting behind me. Those of you who have sat in sound booths know how hard monosyllabic words are to comprehend when one has a hearing loss. My son said that even he was unsure about a couple of the words because they were spoken very slowly, artificially so. When the audiologist gave me the results, she told me I had tested better than any other congenitally deaf person with a CI she'd tested, and that she considered the results very good. I didn't, however! I got 14% of the words (compared with zero percent with my hearing aid) and 58% of the sentences (compared with 5% with my hearing aid). Later my son ran a list of words past me, and I got about 25-30% of them.

My problems with high-frequency sounds showed on the audiogram: I tested at 30 dB except at the highest frequency, which was down to 45-50 dB. She pulled that up in the new map, made some other adjustments in response to my continued gripe about high-pitched sounds, and gave me two new programs plus putting back in my music program.

I feel I'm gradually becoming more and more "free" as I improve my ability to hear. I can call to a family member in another room, hear him acknowledge me, and tell him something. I can catch phrases of conversation in the next room, both at home and in the office.

The TTY is now used only with deaf friends. I no longer use it with family or for most of my business calls. For the latter, I use a VCO phone. Phone conversations still need to be relatively simple, but I am slowly improving my ability to use the phone and absolutely love talking on the phone.

We practice "sentences" perhaps about once a week, and there has been steady improvement. I can now get, on average, half of them, sometimes 3/4, depending on what we are conversing about or materials we are using. Bob sometimes talks to me behind my back, and it's great fun to be able to respond correctly!!

Now that it's spring, I'm being treated to the chirping of birds and other outdoor sounds, some palatable, others indigestible. I can even hear the birds inside the house when the door is open. Armed with 3 bird books, I'm working on identifying their calls. I can't talk enough about how wonderful it is to hear them for the first time in my life. For now I'm focusing more on recognizing different calls, later to be matched to the right bird, with guidance from the more knowledgeable. Just hearing them in the early morning as I step out to go to work puts me in a cheery mood.

Today I was able to hear a neighbor talking on his cell phone, though it was only a muttering sound, and I certainly wouldn't try to eavesdrop!

I am also able to hear the phone ringing upstairs while watching TV downstairs. This surprised me when it first happened because our TV is a bit louder than average since we both are hearing impaired. With the hearing aid, by contrast, I could barely hear the phone when right next to it. Even our door chime is no longer a problem. I can finally hear it from the back of the house.

I can now sit across the room from my elderly mother and converse comfortably with her. Before, I would have had to be practically in her lap. She used to have a strong, clear voice, but in the last few years her voice has become less distinct, softer, and "mumbly." It is such a thrill to be able to talk to her on the phone (simple sentences, remember!) and to recognize her voice on the phone as well as those of other people.

Some of you have said you prefer female voices to male. Not me. Men continue to be easier to understand, while women on the radio and on tapes often sound like children.

One problem I continue to have is an occasional bout with "noise overload." About once every other week I get exposed to so much noise (from various sources) that I'm almost sick from it and MUST have absolute silence for several hours. I had been that way with my hearing aid growing up, and this seems to be a throw-back to that time. Very loud high pitched sounds and steady droning bother me.

"Listening therapy" continues to be a great game for me. I love it because it's a form of self-competition. I stopped the audio tape/book combination temporarily and am now using "English as a second language" tapes as well as a tape called Chicken Soup for the Woman's Soul. These are played over and over. I also continue to listen to the radio as much as possible--general news and financial news. I can understand the weather reports nearly perfectly, about 2/3 of the traffic reports, and about 10% of the general news. I have found that if I listen in the middle of the day, I get about 20-25% because they talk a bit slower then. The shrill screaming of sports announcers pins me to the floor in agony because the sound is like a giant nail file; I can't understand a single word of sports news, nor do I even care!

Seven Months

This is supposed to be a 6-month progress update, since I had my checkup in June, but I am calling it a 7-month report in order to be up to date. Since my last progress post, there has been much improvement in my ability to understand speech, the result of persistence and hard work, the name of the game. It's the strategy I have used in learning to use my cochlear implant to maximum benefit.

Problems I described in the last report are either gone or diminished. Women now finally sound like grown ups, and I can understand some or all of what they say on tape or TV minus lipreading. The rushing of water, the ceaseless roar of our air conditioner in the soggy furnace that Virginia has become this month, and the rattling of grocery bags no longer rattle me! These sounds are rapidly becoming "white noise," at long last. This is a major triumph for me, because I had almost despaired of learning to live with them! It is possible that the new extended frequency software I have been using since mid-May is a contributory factor.

In mid June, right after my 6-month checkup, an odd experience happened which the good folks at Advanced Bionics could not explain at the CICI convention at the end of June. I relate it here in case any of you CI users have had a similar experience. There was a ferocious electric storm that night, and I had been listening to a tape while patched to my battery-operated walkman. While doing so, I was flipping back and forth between programs to try to determine which allowed me to understand the tape best.

Suddenly, I "heard" a hum, just like the one I had heard at the time of my last relapse in March. The hum quickly became a roar, and I turned off the walkman and took off the CI. The next morning I noticed a super-sensitivity to sounds, rather like when one has been in a dark room for several hours and suddenly goes outdoors into a brilliant sunlit day. For the next 7 days I had to keep the volume of my speech processor down, gradually increasing it each day, till I returned to "normal." For the first several days, I experienced brief intermittent "roars" during the day, lasting just a few seconds each time. In the absence of any other explanation, I have concluded it was an episode of tinnitus.

For this reason and because of the mild vertigo I still have, I continue to try to carefully monitor how much high-pitched noise I am exposed to, but the "danger" doesn't seem to be as critical as previously. I am increasingly able to tolerate more and more noise and volume of sound.

I don't have all the scores from the 6-mo. evaluation at Hopkins (the audiologist didn't tabulate them while I was there), but do know the following:

1. The audiologist read 8 paragraphs to me, 4 with lipreading and listening, and 4 with just listening. I was timed to see how long it took me to understand the entire paragraph perfectly. With both "ear" and eye utilized, I got each paragraph right on the first reading--within one minute. Just listening, I got each paragraph right within one to three minutes (varying). She told me most people take 8-10 minutes to comprehend the paragraph just by listening. Since no one else has mentioned this particular test, I don't know how commonly used it is.

2. Phone test: 70% of numbers right, 60% of phrases right.

I don't put much stock by these tests, however, since laboratory conditions are contrived. What's more important is how we do in real life.

And in real life, the telephone has suddenly become almost an obsession. All my life the phone was off limits, something for everyone else to use. It wasn't for me. Telephone accessibility for me, in my deaf days, was limited to the TTY and the relay service. But all that has changed in the past month.

I now can schedule appointments and handle personal business matters on the phone, with NO help from anyone. Talking on the phone is becoming fun, not something to frighten me witless. I actually try to think of people to call or reasons to make a call!! I have even offered to help my husband with a call he was struggling with!! Only someone who has been through a lifetime of never being able to use the phone can understand the giddiness, the breathtaking sense of triumph I have each time I succeed on the phone. I can even get thru voice mail (dialing a second time, however, to "get it"). I don't yet handle the phone perfectly, still asking people to repeat sometimes, not yet completely comfortable with sustained "small-talk" conversations, but the phone barrier is coming down for me!!

And just today I spent 45 minutes on the phone chatting with a friend who, like me, has a CI (for a year now, and uses the phone as well as any hearing person) and had been deaf most of her life. There we were, two women who had been unable to use the phone before getting our implants, talking about

everything imaginable. When we hung up, we both called our husbands to tell them about our breakthrough conversation! Victory has a very sweet flavor.

A month ago I talked to my brother for the first time in our lives. After we hung up, 500 miles apart, we both broke down and wept. The full realization of what I had been missing out on as a deaf person just overwhelmed me at that moment. When you have never had normal hearing, you don't entirely comprehend how much of the world of sound you are missing and how that affects your family relationships and friendships. As I step more and more into the realm of the hearing, I am amazed at the effect my vastly improved hearing has had on my relationship with relatives on both sides of our family and with our hearing friends. On a recent trip north, we made numerous stops to visit friends and relatives, some of whom had been on my list of Tough To Understand. ALL of them were scratched off the list. I could easily understand every single one of them. It was wonderful to be able to sit in a partially darkened room at the end of the day, chatting with a friend, sitting 20 ft. away from me, and not even noticing that it was growing dark, and especially not asking her to REPEAT!!! Just about the only time I ask people to repeat is in noisy situations or if they have a heavy, unfamiliar accent.

A funny thing happened on that trip. During the numerous visits, whenever I overheard someone asking my husband a question, I would immediately answer for him. It was my way of saying, "Hey, look at me, I HEARD that!!!" Heaven knows what they thought, gulp.

It was also on that trip that we met some of you who will be reading this. It was just wonderful getting to know you, and I look forward to sharing experiences and supporting each other in our mutual CI experience. I care about your successes and problems as much as I care about my own. We're all having this adventure together.

Audio tapes have become the cornerstone of my listening therapy. I stopped listening to the radio and began using tapes instead. Each one is played 2 or 3 times, with comprehension increasing each time. How much I understand the first time varies, depending on the narrator, but it ranges from 25 to 40%; the second time, 40-60%; the third time, 60-70%. My goal is to get to 80% comprehension the first time, by Jan. 1st. Before, I couldn't understand female narrators, but now I can. However, I still avoid accented voices. Without those tapes I don't think I would be doing as well as I am now.

We now use a simple, completely portable infrared system to watch TV. The sound quality is stunning, the infrared technology giving a much more pleasant listening experience than my CI alone. Often the captions are turned off. When we are too tired to listen, we'll turn them back on. The point is, we have a choice.

My cochlear implant has given me the most unimaginably valuable gift possible--the gift of inclusion in, and connectedness to, the world surrounding me. This has not been given without demanding something from me in return....Two things: Mild vertigo and the willingness to work hard to develop my listening and hearing skills. So the gift hasn't been free, and that's important to understand. There is no such thing as a free lunch! But this is one lunch I am feasting on to an unbelievable extent and am eager to experience more audio delicacies, including music, as time goes on.

One Year Progress Summary

1997 was one of the most extraordinary years in our lives. In a nutshell, it was the year when I cast aside my deafness and became a “hearing person in process”! You may recall I had just had cochlear implant surgery at the time I wrote our 1996 newsletter. At that time we had no idea what the outcome would be. The results have so enormously changed our lives that I am focusing on this one event to relate to you. This is what happened:

1. All my life I had been unable to use the phone. Now I can chat by the hour with some of my friends and family members. I can also make my own “business” calls.
2. Music meant nothing to me before. Now I love it, especially classical, instrumental and some New Age music. Christmas carols are a special delight for me this season!!
3. I used to need captioning in order to watch TV. Now we watch many programs without captioning, including the nightly news.
4. I had been unable to hear most birds, insects, and frogs previously. Now I can hear all of them and identify several. I listened to the birds by the hour during the spring and summer months! I can even hear them inside the house when the windows aren’t open.
5. I can understand nearly everyone FAR more easily than before, including chatting without looking at the other person, talking in the dark, and talking while driving. I can understand short responses from another room.
6. I now hear all kinds of environmental sounds—car and other motors, airplanes (even inside the house with all windows shut), whistling, wind chimes, footsteps, doors opening and shutting on another floor—the list is endless.
7. Never being able to listen to a radio before, I can now understand about 2/3 overall and sometimes 3/4, depending on the narrator’s voice. I also listen to audio books on my walkman, and understand on average about 60-75%, sometimes as much as 80%.

At Johns Hopkins, where I go for my checkups, I floored the cochlear implant program staff recently by being the only one of their congenitally deaf adult implant users to be able to use the phone. My implant experience, written by me, was published this fall in CONTACT, a magazine for cochlear implant users and professionals in the field. I am now one of the associate editors of the magazine, and my commute these days is to my basement office! I also got written up in a European magazine for parents of deaf and hard of hearing children.

Sounds like bragging, right? You’re right. We love telling people how wonderfully different things are in our household now. The above list is only the tip of the iceberg of change this fabulous new “gadget” has wrought in my life as door after door has opened to me.

A Cruise, from an Auditory Perspective - May/June 1998

In May my husband, Bob, and I took a two-week cruise of Scandinavia and Russia and also visited England. This type of trip I would not have ventured in my hearing aid days, as I hadn't felt I had enough hearing to benefit from a cruise vacation. Cruises are the very epitome of an auditory experience, since there are activities of all kinds on the ship, guided tours ashore, and meals taken in very noisy shipboard dining rooms and in restaurants on land. "Cruisers" constantly contend with background noise, music, and assorted accents, all of which can be intimidating to someone with a hearing loss.

When Bob, who is hard of hearing and wears two hearing aids, and I signed up to take this trip, I decided it would be a gigantic "lab experiment" to assess how well I could function with my implant in such a challenging environment. I knew that the usual preparatory steps would need to be taken to "educate" the cruise line's tour managers about accommodating our hearing loss. Accordingly, I emailed a customer service representative weeks before departure, telling her we wanted to bring our personal FM listening system to use on the tours. She later responded that she had secured the "cooperation" of the various guides.

We found, however, that we didn't need our FM system on the tour buses after all, because in every country the guide spoke into a microphone on the bus, which we heard easily and clearly, even when we couldn't see their faces. We sat in the front of each bus, our seats having been reserved for us by the ship's tour staff, wonderful young men and women who were very careful, without being overbearing, to see that we got on the right tour bus. In addition, they tried to assign us to guides whose English was better; their efforts paid off most of the time, but there were a couple of guides who were virtually incomprehensible-so much so that even the hearing people in our group struggled to understand them. Bob and I were able to watch the passing landscape or cityscape as the guides monologued into their microphones about what we were seeing, the culture of the country, interesting statistics or facts, and illustrative anecdotes. On ground, walking around, we stayed near the guides whenever we wished. This tactic paid off particularly well when we visited the University of Oxford in England after the cruise. Our guide, with his exquisite, precise British accent, had a penchant for gruesome stories about various sites he pointed out to his flock of tourists. Since both of us were right next to him, we got all the gory details, leaving me to muse over whether there can be times when deafness is preferable to hearing.

On the ship, we shared a quiet table at dinner with another couple, dear friends from home, the wife of whom was hard of hearing. Experienced cruisers, they had acclimatized the staff to her listening needs to the point where we had been given a table against the wall at the front of the dining room, away from other tables. The waiters earnestly assured us over and over that this would be "our table" for the duration of the cruise; no one else would be permitted to sit there. With my cochlear implant, however, I could have sat happily at just about any table and managed with my tiny auxiliary microphone, which is usually employed only in noisy situations. With it plugged into my speech processor and my sensitivity dial turned down to mute the background din, I am very much in the midst of the conversation in any restaurant or party. Bob, in the same situations, uses his FM system and joins the conversation with ease. The quietness of our assigned table, however, shows it pays to speak up about one's listening

needs, rather than struggle with communication while dining with others, be they friends or strangers. The all-important evening meal should be relaxing and fun, not torture.

We discovered, to our intense delight, the superb acoustics in the various lounges where lectures, an art auction, music events, and floor shows were held. The P.A. systems were so good that we could easily understand most of what was spoken from many rows back, without lipreading. For me, it was pure heaven, a miracle, the answer to a lifetime of yearning to be able to attend a lecture on an exciting topic and sit back and listen with at least 75% comprehension, with no dependence on anything other than my very own hearing. The art auction was the first I had attended after my implant, and I understood just about everything bellowed out by the auctioneer, except an occasional unfamiliar artist's name. I was thrilled to be able to follow without having to sit right under the auctioneer's nose.

At various airports on this trip, I found that, despite my wonderful "new" hearing, I had to remain as alert as in my "deaf" days, because both Bob and I were only able to understand about one-fourth of the announcements over the PA systems. Airport acoustics and the concomitant noisy bustling, chatter, and clatter are not conducive to auditory accessibility. Thus we relied on our age-old routine of telling the gate personnel that we had a hearing loss and needed to be informed of announcements pertaining to our flight.

Just about everywhere we went, people were willing to accommodate our hearing loss as long as we carefully, in an upbeat, pleasant manner, explained what we needed. Clear, concise communication with hotel concierges, restaurant waiters, cab drivers, and natives on the streets paid off in spades for us, as we look back on a wonderful vacation, during which we encountered few of the communication-related frustrations we had experienced in the past.

In conclusion, some thoughts....

I feel, from my perspective as a cochlear implant user, that my "lab experiment" auditorially was a huge success, as it had been apparent daily that my implant gave me the kind of listening accessibility I had never had before in my life, having been born profoundly deaf. Yet, while the sound barrier was considerably lowered, it was still there. It was there when I struggled with the heavily accented, staccato speech of the head waiter at our table on the ship, when I missed something someone had said to me on a bus, when I had to use my auxiliary microphone in the laundry room to chat with others, when I didn't like the ship's tiny theater because the sound didn't compare in any way with that in a "regular" movie theater, when I only got words and phrases from airport PA systems. This trip made me realize my sense of being hearing impaired will never entirely fade away because it has been too indelibly part of my identity all my life. Having much better hearing doesn't erase years of viewing myself as a deaf person or prevent some people from continuing to treat me as a hearing impaired person. What it has done, among other positive things, is alleviate that conditioning, make it infinitely easier to understand people, allow me to use a regular telephone, and enhance my sense of self-esteem. But deafness is still a psychic companion-not nearly as large as before, but nonetheless there, shadowing me. My focus, since getting my implant, has been, not on my deafness, but on my incredible new hearing, and there it shall remain, as I strive to continue improving my listening skills. I don't mind

the shadow stalking me so long as it doesn't drag me back into the silence of deafness. After all, it's an auditory world we all live in!

1998

Reflections on Using the Phone

Tragedies affect all of us at one time or another, and when they hit, we spend time on the phone sorting things out, making arrangements, and offering and receiving emotional support. I hadn't fully realized how much easier it was for me to cope with what happened to us this past summer because of my ability to use a voice phone.

For example, in July, my husband's cousin called from Massachusetts on an evening when I was alone at home to tell us his sister, who had been like a sister to my husband, had just died. We had known this was coming, that, at the relatively young age of 46, she'd been battling colon cancer, but we had continued to hope. Where there's life, there's hope, after all. As I said, I was alone and took the call, understood everything he was telling me in his rich melodious voice, told him we'd come up for the funeral, and told him where we would stay.

Later, from a motel room in the Boston area, I was able to call a relative to get directions to the funeral home, just using a regular phone. While I had to ask her to repeat unfamiliar street names, to be sure, I still got accurate directions without needing to rely on someone else to help us out.

A few weeks after that, in mid-August, I got a call from my mother telling us that my brother's 5-yr. old daughter, who has had leukemia for 4 years, had just had a second relapse and was in the hospital. I could hear the terrible fear in my mother's voice, the worry that was overwhelming her, and did my best to calm her down. By the time we had hung up, she was feeling a bit better, and this was only possible because I was able to talk directly with her, soothingly. We could hear each other's voices and share what we were feeling. I talked several nights later with my brother himself, and we discussed the situation his daughter was facing, the bone marrow transplant that will take place probably around January (there are eleven potential donors), and the arrangements he and his wife had made in an effort to keep their household running during this crisis. I could pick up all the emotions in his voice, the long pauses, the stress, even what he was saying in an aside to his other child.

At the end of August, I learned via a phone call that a dear friend of mine had been murdered a few days earlier. Stunned and in disbelief, trying to absorb this totally unexpected news (who ever expects to hear about the murder of someone whom we know?), I spent the next two hours on the phone with various people, sharing.

Sharing is what this is all about. Being able to use the phone, even though I do not understand 100% of what the other person on the phone is saying, brings me into the reality of the lives of my hearing family members and friends, and lets us interact in a way that simply is not possible with a TTY. Deaf people may take to TTYs like ducks to water, but not hearing people, and I am thankful that those who need to use TTYs have this technology and thus aren't cut off from phone use. There is, however, an intimacy, a

smoothness to voice-to-voice communication that is missing with TTY-to-TTY communication. Being able to share the bad cards life occasionally deals us with my hearing family members and friends via telephone conversations has made me really feel part of the hearing world, where I have always felt I belonged despite having been profoundly deaf since birth.

A note I want to add here, as I want to be very, very honest about my cochlear implant experience, lest people misjudge my capabilities. I am not always good on the phone. I have found that factors affecting my phone performance include telephones themselves (cell phones, cordless phones, regular phones), noise on the phone line when I am placing or receiving a call (when it is a problem, I turn my sensitivity dial down, but that means I sacrifice some consonant comprehension), fatigue, noise surrounding me (such as our dishwasher), and the speech of the person I am talking with. If that person is a stranger, I may have trouble understanding initially who s/he is; if s/he has an accent, the problem of figuring out who he is, is compounded. I have trouble with telemarketers and very often just quietly hang up once I have determined that is the caller. I converse by the hour with friends and family members who have clear or familiar speech. If I need to make a call that involves a very complex discussion in which I MUST understand every single word, I will use my VCO phone; I choose that option, however, only once or twice a month now, two years after receiving my implant. Using a regular phone, which has a volume control and a PhoneMate attached and plugged directly to my speech processor, I schedule and cancel appointments, order items from catalogs, call catalog companies with questions or problems, renew library books or tapes, get directions to a location, track down addresses and phone numbers, and conduct all personal and social calls.

Socializing: A Few Notes

On a Saturday afternoon in mid-November I was in a supermarket, heading down an aisle, oblivious to people around me, when I suddenly heard my name called. I spun around and saw a couple who live in our former neighborhood. After some excited chatter, we agreed my husband and I would come over to their home that evening, and a third couple, whom we also knew from those long-ago days, would join us. What a difference my CI made that night! I kept up with the rapid back and forth of our 6-way conversation, only here and there missing a remark, but still feeling very much part of the group, always knowing what the topic of the moment was, and able to laugh at their stories or one-liners and to make them laugh in turn. It really made me feel good about my "new" hearing.

I am now suddenly finding myself in the very odd position of beginning to hear slightly better than some people with whom we've been friends for years. We visited old friends recently in Essex, Connecticut, whom we hadn't seen in over a year. The husband told us he now had some high-frequency hearing loss, and his wife said she'd noticed he was turning the TV up louder. It became apparent that I had more high frequency hearing than he did, even though he still heard better than I do, overall. I would never have thought in a thousand years I'd find myself on the other side of the table, so to speak. It also struck me as incredibly wonderful that my friend and I could sit in another room while our husbands were watching a ball game, each of us plugged to our portable CD players listening to one another's CDs, comparing notes. This, indeed, made me feel very plugged into the world.

Some Restaurant Stories

During Thanksgiving weekend my husband and I went out to dinner at a very crowded, popular restaurant, where the restrooms were upstairs. I went up to track down the ladies' room before sitting down to dinner. Unable to find it, I asked a lady having a cigarette in the hallway where it was. Afterward I headed back down the hall and, just after I passed the woman, I distinctly heard her ask, "Did you find it?" Without missing a beat, I called back, "Yes, I did."

On another occasion, as we were leaving a restaurant, a party was entering. A man I had just passed said, behind me, "Was your dinner good?" I turned and called back to him, "Very good!"

Those two little anecdotes illustrate how easily a person who doesn't hear can be thought of as rude by hearing people they encounter.

But hearing people can be unintentionally rude, as well. A waitress at our table in a restaurant, while knowing all of us as patrons, told the sole hearing person at our table that she was learning sign language, especially fingerspelling, to communicate with deaf customers. Even though she knew full well that I was deaf and had a cochlear implant, she directed her remarks to the hearing person only.

In the Car

I am now able to clip a tiny auxiliary microphone at my collar, on the passenger side when I am driving, leaving my speech processor dials at their normal setting, and chat away with the person sitting beside me. I can pick up a little of what a person in the back seat is saying, also.

Talking from Separate Rooms

Visiting my mother recently, I was sitting in the living room while she was in the kitchen, 20 feet away, out of sight. We were able to trade one-line comments back and forth, without her having to come out to face me. I also was able to understand a question called to me in the living room from my mother in her bedroom, 30 feet away, out of eyeshot.

1999

Notes on Music Enjoyment

Since I have been profoundly deaf all my life, with no music memory, my response to music may possibly be of interest to professionals, parents, or even other CI users. Only after getting my cochlear implant did I begin to perceive what "all the fuss was" about music, so I am still evolving.

When I concentrate on listening to instrumental music (and not do something else while listening)--usually classical but occasionally New Age and mood music--the sounds paint images in my mind, such as flowing rivers or waterfalls, various types of dancing, people sharing "sacred" moments with one another, and so forth. An art lover, I try to visualize the paintings that might emerge from the music. Some music absolutely elates me, such as that of Mozart and Rachmaninoff, other music sounds more stately and calm. The impressionism of Debussy is very moving, and as I listen to him I think of my

favorite Impressionist artists and their canvases. I am just now getting to the point of almost crying over particularly beautiful music. I have gotten goose-bumpy listening to certain pieces, such as "Conversations With God," disc 1. Yet, despite the rich benefit I get from music, it's important that understand that I will never be able to bring music into my soul and intellect in the same way as people who have normal hearing.

As I putter around my kitchen, my boombox is usually on. Listening to music makes food preparation infinitely more pleasant, and time passes much more quickly. I also love to listen to music while driving on a long trip. When I'm the passenger, I'll switch to an audiobook, which requires more concentration.

So far, the piano, harpsichord, harp, guitar, and flute are my favorite instruments, but the horn and organ, neither of which I liked during my first year of "implanthood," now sound very good to me. I also am starting to like drums and am reacting far more to rhythm than I did a year ago. I also am paying more attention to harmonics and melodies than previously, in an attempt to understand beneath the sounds I hear. I am not crazy yet about hearing singing along with the instrument(s) playing, but Enya is one performer whose singing is truly beautiful-a very haunting voice.

Many implant users who were originally hearing have said that music enjoyment gets better and better over time. This has certainly been true for me! Being able to wander among and explore the indescribably delicious riches of the music world has been a totally unexpected bonanza of my implant experience.