

My Bionic Ear

Joan S. Birman

This is the story of how I lost my hearing, and how it was rebuilt 47 years later, with the help of computers.

The story begins sometime in 1963. I was 36 years old, and had 3 children, all of whom had had the mumps a few weeks earlier – first 7-year old Ken, then 6-year old Debbie, and finally 2-year old David. After they had all recovered, I resumed my part time job. The day I first noticed that something was amiss, I had called home from work at 5:00 PM to tell the baby sitter that I was on my way home, but to my surprise could not hear anything on the telephone when I held it to my left ear. Switching to my right ear, I could hear. Puzzled, I left for home. When I woke up the next morning I realized that I had the mumps. My hearing loss persisted, and I was dizzy, nauseous, and disoriented too. Our children’s pediatrician, Dr. Robert Scalatar, seemed to understand this strange disease much better than my own internist or the ENT specialists that I saw, but after a little while he said he really couldn’t take me on as his patient.

Several months and several doctors later, I finally understood what had happened. The mumps virus had destroyed the hair follicles in my left ear. I had what was called ‘nerve deafness’ (but more on that below) in that ear, and was told that there was no way to regrow the hairs, I would never again have normal hearing in that ear. My balance, which had always been easy and natural, was another big problem with no solution. My sense of directionality of sound was gone too, totally. In 2010 (as I write this) the problem is well-understood, but in 1963 I was on my own.

1963-2009: When I caught the mumps, I had been a graduate student, studying for my PhD in Mathematics, and I became increasingly absorbed in my studies. With no viable alternatives, I learned to accept the loss. Walking with my children or husband, a steady hand was always welcome help. I did not realize until much later that I had become an expert lip-reader. I re-learned how to drive our car, by using the body of the car as a ‘frame’ to orient myself. In some way that I can’t describe, I learned to balance on a bicycle again, although it’s still hard for me to walk in a straight line. I learned to sit in front of a class or seminar, to work with others one-on-one, in quiet places. I devoured every book on hearing loss and deafness, and followed up many suggestions for new medical opinions, but they were all dead-ends. My husband, Joseph Birman, was invariably supportive, but the truth is that his life became limited as mine did. Foreign films with subtitles, or a DVD with closed captions, gradually became our favorites. I had been aware of cochlear implants from day 1, but had been told (several times) that they were not for me.

After some number of false starts I finally found an audiologist I liked, Mark Hansen. Mark tested me, and fitted me with the first of many hearing aids, all of them ‘bicross”, that is, the aid picked up sound on the deaf side (for example if someone was standing on that side and talking to me) and sent it into the non-deaf side, which fortunately only needed a small boost. Friends and eventually students all knew of my ‘disability’ and accommodated to it. As the years went on digital aids replaced analogue aids, although bicross digitals were very small part of the market, so that the best technology was always a few years behind for me.

With the passage of time, my ‘good’ ear slowly deteriorated. The problems began to be more and more serious. Teaching eventually got to be very hard, because often I could not understand the questions asked by students. After participating in a few excruciatingly embarrassing panel discussions, when I could not hear what the other panelists were saying, I decided no more of that. Collegiate interchanges also became difficult: there were times when I could not follow the discussion at meetings of the department Executive Committee, and that was a source of real embarrassment. Professional meetings could also be uncomfortable. I would ask colleagues questions and then not be able to understand their answers. In 2004, at age 77, I decided to retire from teaching. My social life began to center more and more on e-mail interchanges. I can’t say that I was really depressed about it, because it was simply part of what it was like to be me, but I understood very well that it was not good.

December 2009 to March 2010: In early December 2009 I passed by the Solomon-Shotland Audio Clinic, located on the grounds of the Burke Center for Rehabilitative Medicine in White Plains, NY. I knew that Burke Center, on a lavish campus in White Plains, near our home, is a fine modern facility, and decided it could not hurt to have a new evaluation. To my surprise, the audiologist I saw, Donna Ronan, had technology that was a world away from Mark Hansen's battery-powered hand-held computer, used to program my Widex aid. In addition to reprogramming my hearing aid, which in itself made a big difference, Donna suggested that I contact the NYU Cochlear Implant Center, and told me who to call.

I filled out the required application form, and ultimately was told that yes, I was a potential candidate for evaluation for a cochlear implant, and was given an appointment with Carie Page, one of their staff audiologists. The waiting room at the Cochlear Implant Center was filled with very young children and their parents, and also some number of adults chattering animatedly in ASL.

Donna had been terrific, but still I was pretty astonished by Carie's sharp understanding of what it was like to live with minimal hearing. She was simply the best-informed person I had ever met about the life of the hearing-impaired. She also gave me more thorough tests than I had ever had, in all those years. Her report confirmed my own sense of it. She wrote *Mrs Birman presents sudden profound sensorineural loss in the left ear 47 years ago, and progressive severe to profound sensorineural hearing loss in the right ear*. She told me that whether I could be helped by an implant would depend on whether the auditory nerves were still capable of response. (Hmm, so maybe it wasn't *nerve deafness* after all.) She also told me that Dr. John Roland, a surgeon, could do a test. I learned that it had only been a year or two since people my age (just under 83 at the time) were accepted for cochlear implant surgery.

5:00 PM, March 22, 2010: I found myself in Dr. Roland's office for a crucial test. The hair follicles in my left ear had indeed been destroyed 47 years earlier, but perhaps the nerves that carried sound from the cochlear (in between the the hair follicles and the brain in the hearing process) to the brain had not atrophied. If the nerves were alive, I could indeed be helped. Dr Roland anesthetized my eardrum and inserted a probe through a small hole. Bill Shapiro, the head of the NYU Cochlear Implant Center, stimulated the wire. To my astonishment (and, my husband Joe told me, his and theirs too), I heard every beep, the first time that ear had heard anything in all those years. I learned since then that my situation, with that 47 year loss, was near the limit of their experience. After a good long cry, I made an appointment for cochlear implant surgery.

May 7, 2010: Dr. Roland implanted a tiny computer board, roughly 1x1x.2 inches, under the scalp behind my left ear, 1 mm. from my facial nerve, and close to the cortex of my brain. The surgery was done under total anesthesia, and required one (uncomfortable) night in the hospital, but was otherwise minor for me. The device and the scar are inconspicuous, almost invisible. The device was manufactured by Advanced Bionics in California. On May 26, roughly 3 weeks from the surgery date, it will be 'activated'. As I write this, on May 10, I feel a bit disoriented, tired and restless, but basically well.

May 26, 2010, Activation: I had been told the sounds I would hear would be unlike anything I had ever heard before, and that was true! There is no question that I am hearing again. The sound is all around me (not sharply directional, as with my "good" ear, and not limited to what I want to hear either.) But the sounds are not meaningful. Lots of banging, some sounds like wind rushing by my ear, some sizzling noises. White noise, but also tap water in the sink, the flushing toilet and the refrigerator motor have returned to rejoin my experience of the world. It feels as if an airplane runway was built a block away from our home! Carie Page, my audiologist, tells me the white noise is from inside the cochlear, and is transitory; as for the refrigerator motor and other normal environmental noises, my brain has to learn to pay attention to what's important and ignore what is not. My two computers, the implant (courtesy of Advanced Bionics) and my brain have to learn to cooperate. Carie's programming seeks a comfortable level of sound.

Day 8, June 3, 2010: Today, 8 days after activation, I am familiar with the mechanics of my newest gadget. At first it was uncomfortable to wear, as my ear felt sore, but I'm not noticing that any more. I

can also find the place the magnet attaches (covered by hair, it's very inconspicuous) easily, change batteries, understand all the parts etc. I organized places to keep everything, and don't have to hunt to find what I need.

When someone speaks I notice special banging sounds. They are rhythmic and very accurate renditions of the speech pattern, without being meaningful in any way. With some imagination, I could see how all that banging could turn into spoken words, because the rhythm is exactly right.

Are there any sounds I can recognize? Yes, the water running in the kitchen sink is a sizzle that's special, and the toilet flushing is yet another. I no longer confuse them with other background sizzles that are more like white noise. When I type at the computer keyboard, I hear regular banging.

When I listen carefully I realize that some of that background noise is highly meaningful. With my good ear I know I'm typing, a dog is barking, a bird is chirping and stops, children are playing, someone is speaking to me. The car directional signal comes through loud and clear, and stops at the right instant.

On the down side: it's very tiring to wear the processor all day, and it's still an impediment to understanding what people are saying to me, when I need to understand.

The program associated to "switch up", "white space down" seems the best choice, although 'best' is very imprecise.

Do babies learn to speak this way? How could we possibly know?

Day 10 – June 5, 2010: Today was very exciting, because I now understand that with time and practice speech actually could emerge from all those "shsh.." and banging noises!

Saw Beth Dobbyn (the Speech Pathologist at the Cochlear Implant Center) for the first time. She tested me on word pairs: first 'ball' and 'apple'. She said both, I listened with my right ear hearing aid turned off, the processor on. Of course 'ball' has 1 syllable and 'apple' has 2, and I had already noticed that I could detect that difference. She covered her mouth with a large round plate, and said one of them, and I guessed correctly. We went on to many other word pairs, some with 3 syllables, and I heard the correct one. Then she added one more pair, 'sock' and 'shoe', and the "sh..." was different from the 'ss...', and I could hear it. Then we did 4 at a time, and 6, and finally she tried a hard one: 'foot' and 'fat'. At first I could not tell, but then she pointed out that the 'oo...' in foot was more drawn-out than the 'a' in fat, and she was right, I could hear it. Yes, I will learn to hear and understand speech with my left ear.

Beth was noncommittal about whether I will be able to hear well enough to understand what is going on, using just the processor.

Day 12 – June 7, 2010: This morning I was aware of a brief period when my ear was no longer assaulted by background noises that had no meaning. The quiet was good. Also, I listened to the 6:30 PM News on Channel 4, and had an improved sense that I was hearing speech (however I was also reading lips, hearing with the Widex hearing aid on my right ear, and watching closed captions).

Week 4 begins – June 17, 2010: Listening to the news on Public Radio, I experimented and turned off my hearing aid to try listening with just the processor. I can hear all the rhythms and patterns of speech, but they are blurred, like the dialogue in a Swedish movie without subtitles. But suddenly, clear as could be, "at 7:30 in the morning" emerged out of all that junk, followed a little later by "xxzvbbxxx...a matter of policy...fsdrw", and then in a rhythm that I recognized as someone signing off, "bxbxbxbxbxbccff...in Jerusalem". Immediately, another voice (also xxzbbccxx but somehow different, began to speak.

I immediately went to the Internet to see what had happened in Jerusalem at 7:30 AM – indeed, there were near riots when the police arrested a group of ultra-Orthodox ‘Ashkenazi’ men who had insisted that their daughters be separated from more liberal-thinking (but also orthodox) ‘Sephardic’ girls their age, in a public (but religious) school, by putting up a wall in the school and erecting a fence in the recess area. The courts supported the police, and the entire orthodox community had turned out, 20,000 strong, to protest as the paddy wagon took them to jail.

2 days later: That little hearing episode ended, but this AM Joe was driving and talking and I was the passenger, so again I removed my hearing aid and he said “tell me what you hear”. I told him I wasn’t making much sense out of what he was saying, but confessed that his last words sounded most like “fuck you eight”!!! He said “hmm” and repeated them, but no use, it sounded to me as if he was just repeating “fuck you eight”. Finally, I turned on my hearing aid he told me the word was “fluctuate” – close, when you get right down to it, but the devil is in the details! I laughed so much that the tears rolled down, it was just so funny.

6 weeks from activation: July 8, 2010: I am hearing much much more of intelligible speech, albeit the voices are flat and lack texture. A good surprise today: Harriet Moser came to work with me. The last time she was here I had to turn the processor off to be able to talk about mathematics, the competing sounds were simply too distracting. But today I didn’t need to turn it off, and in fact as we were talking I realized that the implant was actually helping me to hear her better – a milestone!

August 15, 2010, a 3 month checkup: Carie gave me a battery of tests, so that we could compare my hearing before and after the implant. I am normally not one to be pleased by a grade of 30% on an exam, but considering that I heard nothing in my left ear 3 months ago, understanding 30% of the spoken words on Carie’s list, with just the bionic ear, is real progress. I finally understand that I need to use *everything*: my bionic left ear, my Widex hearing aid in my right ear and lip-reading. With all that, as the tests showed, I’ve come a very long way.

October 8, 2010, 6 months after activation: A very different milestone: I asked our 4 year old grandson Jared Birman what he did in school that day, and he answered “We put on our backpacks to go home.” Now that kind of answer was not what I expected all the times I had felt heartbroken when my grandchildren tried to tell me something, and I didn’t understand them. Still, I actually understood what he had said, and that was profound. I am so grateful to have understood about the backpack. It opens so many doors to interactions that I had truly missed.

May 8, 2011: The white noise sounds are totally gone. When I’m in a quiet place, it’s quiet. In a quiet enough setting, I can understand speech and have a meaningful conversation with just the left ear and its implant and lip-reading. That’s *very* important, because it means I will never have to experience the isolation of being totally deaf, even if my ‘good ear’ gets worse. True, the sound quality is a little bit like one might expect from a talking dog, but it’s meaningful speech, and that’s enormous. I attended a math meeting in Columbus Ohio this past week, and could hear almost every lecture, and if that talking dog has something that’s as deep to say as my colleagues did, then I feel very good to be able to hear them say it. I had many meaningful math conversations too, and was even happy at a noisy party one evening, just to be with my colleagues-friends and feel so much a part of my professional community. It was a special pleasure to meet new grad students and be able to talk to them, and hear their answers.

I feel incredibly fortunate to be given this new chance to increase my participation in life, at age 83+. And yes, it gets better every day, and I am told that will continue.