

My Story... by *Karen Lichtefeld*

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Since I have been a member of the Hearing Loss Association, I am amazed at the numerous hearing disorders affecting our members. I have a very rare disorder known as NF2 (Neurofibromatosis Type 2). It is a genetic disorder marked by benign bilateral acoustic tumors and spinal and nerve tumors throughout the body. There are several forms of the disease and I have a milder case that is known as spontaneous Mosaic. I did not inherit the disease from an immediate family member and I have only the bilateral acoustic tumors. The disease is so rare that I have only met 3 other people in Kentucky with this disease. Through the internet, we have a National Registry which has brought hundreds of patients together for information & support, much like HLAA.

When I was in my twenties, I started having trouble hearing when on the phone. It was discovered that I had an Acoustic Neuroma on my left acoustic, facial & balance nerves. This was in the early 1980's & MRI was still not in use. I went to Vanderbilt University in Nashville for Neurosurgery because so few surgeons in Louisville had ever removed one. The surgery was successful but I lost complete hearing in my left ear. I went back to work after 6 weeks and considered myself very lucky that the tumor was benign and was discovered so early. Some patients do not have symptoms until the tumor is quite large. Having only the hearing on my right side never bothered me unless someone whispered to me in my bad ear.

About 15 years later in 1995, I had just retired from my job in sales & marketing so that my husband & I could travel. We were returning from a trip when I had a sudden ringing & echo in my ear when we landed. It did not go away after several days so I saw my ENT who immediately ordered an MRI. It was discovered that I had another Acoustic Neuroma in my right ear which is a diagnosis of NF2. The ENT's and Neurosurgeons were blunt in telling me that I would be deaf upon removal of this tumor. My whole world changed in a day and for the next several months I was in a state of terror. I lost 10 pounds and many people thought I had cancer.

Finally, my husband found Dr. Alan Nissan at the University of Louisville Audiology Department. He was knowledgeable in this disease and told me that I needed to see Dr. Darold Brackmann of the House Ear Institute in Los Angeles. I met with Dr. Brackmann & the Neurology/Otology team several months later. This is the part of my story that I consider a miracle. The House

team had invented a device called an Auditory Brain Stem Implant (ABI). The internal parts of my ear are in perfect condition. But removing my tumors results in the severing of the acoustic nerve. The ABI is much like the outer portion of the Cochlear Implant. But unlike a CI which is implanted in the Cochlea, the ABI is a computer chip which is attached to the brain stem. The energy signals and stimulates the part of the brain that understands hearing and language and bypasses the acoustic nerve. When my second tumor was removed, I was implanted with the ABI during an 8 hour surgery in Los Angeles. I was completely deaf for 2 months during healing and before my device was activated. As most CI recipients are aware, the most wonderful sound ever heard are the beep tones of activation! It took about a year to relearn & interpret the new sound. The sound is not as clear as the CI but with lip reading, I can understand about 80% of conversation now. I am technically deaf - yet, I consider myself a hearing person through technology.

I have received so many gifts on my road to re-hearing. One of the greatest is the friendship, support, education and astounding people I have met through the Hearing Loss Association. Hearing loss is a daily struggle! I could not imagine my life without the information that I received from our Chapter when I was first struggling with my hearing loss. I continue to learn & use safety devices for hearing impaired persons such as captioned phones & smart phones, hearing loops, areas of advocacy and information from all KY Chapters. Please spread the word of support that our chapters offer to anyone that is suffering. You will definitely change their life!