

My Story... by Ed Schickel

DEAF IN ONE EAR AND CAN'T HEAR OUT OF THE OTHER!!

I have been asked many times when did I start losing my hearing and why. In reality, it is very hard to know. Growing up, it was a family joke: “Are you deaf in one ear and can’t hear out of the other?” “Go wash your ears out so you can hear!”

In hindsight, I can remember issues as far back as the first grade. In almost every area, I was in the “bluebirds” group. In Phonics, however, I was in the “blackbirds” group. After Christmas, our group started over from scratch. It was strange that I could look at the picture or word and tell you the sound (much from memorization). But, if you said the sound, I couldn’t tell you what it was. For example: I could say a long ‘A’ sound but was not able to hear it back consistently. Throughout my school years, I always found it more comfortable to sit near the front. I didn’t want to be in the first seat, they got called on too often. I didn’t want to sit near the back. It just didn’t feel right. In school, I made good grades but had to work for them.

Over the years, I missed school because of sinus and ear infections. In high school, I had a sinus headache three out of five days. I took a lot of over the counter sinus medications, pills and sprays. I also took aspirin very frequently. Now I am sure the combination of infections and ototoxic medications played a major role in my hearing loss.

After high school, I worked my way through college by driving a truck, carrying hod and mixing plaster, and working in a tobacco factory. This meant that I was working around very loud machinery without ear protection. I can remember going to a doctor with an ear ache only to discover that my ears were impacted with wax. My body was trying to protect my hearing. The doctor accused me of using Q’Tips. I never thought of it until he mentioned it.

After graduating from IU, I started teaching. I was always on my feet moving around the classroom and received high commendations for class management. Now, I know that I was moving around so that I could hear the students. I would often know that they were talking. I was sharp about that. I just didn’t know what they were saying. Like my mother, I bluffed a lot. (Both my mother and father had hearing loss. Dad lost his in a lightning strike, mom with age.)

After I received my Masters from Xavier University, I attended a training program in Washington, D.C. We were a small group in a very large hotel conference room. Each of us had to role play being a counselor and client. When it was my turn, I was very nervous, both because

of the natural stress of being “on stage” in front of my peers and because I had trouble hearing in the room with echoes. I sat down and quickly leaned toward the “client.” I scooted my chair closer. Immediately the instructor stopped the class and pointed out my “attending skills.” I was so proud. Though, all I wanted to do was to hear.

In hindsight, it seems strange that not once did I, my family, or any medical professional ever suggest or think about my having a hearing test. Between 1980 and 1990, I had had four surgeries on my sinuses. I was talking to my ENT when I mentioned that I was having trouble hearing my wife. He quickly quipped “Do you want to?” I said that maybe I needed something. (I was not thinking of hearing aids.) He had me to come back and have my hearing tested. After seeing the results he added a 2nd test that involved being hooked up to an EEG. The audiologist suggested that I just nap while she ran the test. I assume she tried tones at different frequencies and decibels while I relaxed. She read what was happening on the EEG. After it was over, the doctor said I had a mild to moderate sensorineural hearing loss. I could get hearing aids if I wanted or not. He gave me a list of audiologists to see. Later, I discovered they were all Instrument Specialists even though they were referred to as audiologists. I chose one that was close to my home. She tested me again and recommended aids. I purchased my first in the ear hearing aid. The next year I purchased an aid for my other ear. Within 3 years, I purchased another more powerful behind the ear set.

Around 1997 I was tested for sleep apnea and started on a C-Pap machine. No one talked about sinus issues and a C-Pap. In the fine print, it said not to use the machine if I had a sinus infection. I had a sinus infection all of the time. I joined a support group and started asking questions especially about hearing. I was retested and found that the C-Pap machine was set too high and that I should not use it with an infection. My hearing decreased very rapidly during this time period.

In 2000, I had my first job issue. I had a client who had attempted suicide by overdosing. He called my office for help. I could not understand him on the phone. For all practical purposes, he was drunk. He was slurring words and was barely conscious. Normally, I would have been alone in the building. My supervisor happened to be there that day. I got her on the phone. She talked to him and we got an ambulance to his hotel room.

About six months later, I had another incident. I had a female client who had a DUI. Her situation was very serious in that her children were in the car. In KY, this could mean five or more years in jail for wanton endangerment of a minor. Her children were already under state custody. She was crying and I couldn’t understand. I thought I did; I didn’t. After she left, I found out that there was a warrant for her arrest for failure to appear in court. I should have done a suicide assessment and I didn’t. We found her before anything happened.

My employer felt that this was too much, shifted my duties, and said I had to find another safe job within the company that I could do or resign. I could not. I finally took their disability program. This was a hard blow because it also meant closing my private practice. I had dreamed of a private practice for more than 20 years and had just opened it part time two years earlier. Now, I had to close it. I lost a 20 year dream.

During this process, I changed my audiologist. I shifted to University Audiologists. My thinking was that they would be on top of all new innovations. I was tested by one of the professors and assigned to a student. He tested me several times and kept saying my hearing was not that bad. I said, I could not hear. Finally, I phrased it differently. I said I could not understand. "Oh, let's try something else" and he gave me a test that involved listening to sentences and a paragraph. Afterwards, he came out and said "you just don't understand." DUH! "That's what I told you."

He introduced me to Phonak hearing aids with an FM microphone. It was wonderful. The only problem was that my court ordered clients would not talk if there was a microphone in the room.

A psychologist by the name of Carol Holmes introduced me to Self Help for Hard of Hearing people (SHHH) now called Hearing Loss Association of America (HLAA). After my first meeting I didn't think I would go back. My wife encouraged me. I did. They were a bunch of old people (all my age). A member, Dale Hottle, would greet me at each meeting, ask how I was doing and what help did I need. He would sit near me to offer support. I continued to attend the meetings at the Louisville Public Library. At that time they had three meetings per month. One was the standard speaker meeting on the second Tuesday. The next was an informal get together at a restaurant on the fourth Saturday. We also had a captioned movie dinner when the Stonybrook Theaters had a captioned movie. I really enjoyed the social aspect. I made friends who were like me. I became less isolated. I was not alone.

Out of the blue, Paula Esterle asked me if I would like to go to training in D.C., all expenses paid. I jumped on it--only to discover that it was "leadership training". She was grooming me to be the next chapter president. I not only attended that training, I also attended Hearing Assistive Technology (HAT) training in Chicago. I became SHHH Kentuckiana's president and began presenting on HAT. After attending a couple of National Conventions, I started to present on other topics. (When I attend a convention/training, I focus on the education program with the intent of bringing it back home. In that sense, the National Convention became a trainer of trainers program for me).

HLAA is a self-help organization. It is in helping others that we help ourselves. I discovered that mainly through the HAT training. I was totally unaware of "Assistive Devices" other than hearing aids. I now have a captioned phone and a "whole house" alerting system which shakes

my bed and flashes lights when the phone, doorbell, alarm clock or smoke alarm rings. With HAT devices one can remain independent much longer. One is safer.

Memory is the process by which I forget, but I believe it was Bob Stuckey who set up a meeting with Patrice Blanchard at AARP. I became an AARP volunteer to share what I knew about hearing loss. Patrice was able to connect me to the AARP chapters. By 2005, I was doing more than 20 presentations on hearing loss issues per year throughout KY. I now do about four or five.

SHHH volunteered each year to staff the KY Commission on the Deaf and Hard of Hearing (KCDHH) booth at the state fair. I suggested we do more. The next year we partnered with KCDHH. The next year we had our own HLAA booth. In subsequent years we partnered with Heuser Hearing Institute. As they limited their involvement of other programs, we backed out and became volunteers for Heuser at the state fair while still talking about HLAA.

After Mary Lee resigned as State Chapter Coordinator for HLAA, Paula Esterle accepted the role. Later I joined her as a Co-State Chapter Coordinator. In reality, I did little to promote chapters at that time. I focused on presentations throughout KY, IN, OH, and TN. I presented at HUD conferences, Vanderbilt University, Murray University, U. of L., and at many senior groups.

In 2007, Becky Crawford, Marilyn Fenwick, Carlene Ballard and I were commuting almost an hour each way to the HLAA Kentuckiana meetings in Louisville. Becky was saying that we should have our own meeting in Bardstown. With that, HLAA KY Home became a formal chapter in August of 2009.

Over the years, my hearing has steadily decreased. After attending many National Conventions and doing a lot of homework, I took the steps to obtain a cochlear implant (CI) in 2005. My Advance Bionics CI has moved me from being nearly deaf to understanding 80% of oral communications. I still have issues, particularly in noise, but I function more normally. This past winter I was invited to participate in a CI research project. Connie and I flew to California to participate in the program. Again, I get the privilege of helping others by what they learn from me while helping myself. I am honored.

When I look back, the thing that most strikes me is how clueless I was about hearing loss. I was not only clueless, my family, my doctors, my employers were all clueless. I just hummed along like that was life and there were other things more important to think about and do. It never really dawned on me that I had a hearing loss. In fact, my secretary once told me that another therapist was upset that I didn't respond to him when he was just behind me. She told him he could never talk to me from behind. I wouldn't hear him. She knew before I did and was

responding to my needs (Amy was A Great Secretary!). SHHH/HLAA outed my problem and helped me to want to do something about it. In order to self-help, I had to help others. Now that I am retired, it is a major purpose for my life. HLAA has brought me comradery and friendships beyond compare.

Now it is important to note that SHHH/HLAA has made an important contribution to who I am today. More than that, it connected me to my friends and mentors, Paula Esterle and Mary Lee, who are the primary impetus and guides to my coping with hearing loss and my role in assisting people with hearing loss. I have stood on their shoulders for many years.

I have been blessed.

Ed Schickel