

Paula Esterle is the former HLAA KY State Chapter Coordinator and a past President of the Hearing Loss Association of America's Kentuckiana chapter. She has been a very active and supportive board member of HLAA Kentuckiana. HLAA-KY Home owe her a great deal for her support and advice.



My Story...

I Came for Knowledge and Remain with Friends...

Support is an important part of our mission statement for the Hearing Loss Association of America. One way to address that is by sharing our stories and experiences--informative, funny, triumphant, sad, or frustrating as they may be. Currently, the big story is about a group of inexperienced people who were told they would probably not be successful but still pursued a conference on hearing issues in a predominantly rural state against many obstacles. I would like all to know that the KY Chapters will be putting on their second absolutely amazing conference in 2015 with the goal of teaching coping and advocacy. The proceeds will support the needs of the four growing chapters. It will be held in Louisville on September 11-12 with details at www.HLAA-KY.org

I wish I had the information HLAA offers in the dark ages of the late seventies when my hearing began to seriously deteriorate. There was no connecting to the internet and the professionals believed the primitive hearing aids were all that I needed. Now, I am more well informed because being a member of HLAA has taught me what can be done to optimize my

hearing such as RIC hearing aids, visual alarms, Bluetooth, positioning, ALD's, CART or perhaps even someday a CI. We need to know preferred communication styles and be acquainted with various types of assistance in order to best understand one another. "Can everyone hear me?" That question is always asked before we get started at our Hearing Loss Association informational meetings.

I am originally from Northern Indiana but from Louisville for the last 35 years. I am a previous HLAA Kentuckiana chapter president and was the state chapter coordinator in Kentucky for eleven years. Direct all complaints and negative comments to the current state coordinator and other leaders and just save the good stuff for me. ;-) I will never forget my first SHHH meeting (HLAA was then called Self Help for Hard of Hearing People) when I walked into a situation before high powered digital hearing aids and cochlear implants were common. I needed varying communication styles from signing to simply writing on paper. The effort to communicate with people like myself was more frustrating than I had realized. So, this was what was so challenging for all of the hearing people around me. Well, I had been working hard to comprehend too and with understanding and practice, the situation improved. The people in my life had already adjusted to facing me and speaking clearly over the years but the rest of the world had not quite gotten the message. Within the group we knew how to communicate with one another.

My personal history is common in that many people have sensorineural loss yet is unique in other ways. There is a genetic component tracing from my maternal great-grandmother's side. I also have a sister with nearly identical bilateral hearing loss with both of us sharing a profound loss in the left ear and a right ear about at a 60 dB loss straight across all frequencies. I had near normal hearing in one ear until my twenties which meant I only needed to sit at the front left side of the classroom in school and had no problems. I am now very grateful that I was taught speechreading in Kindergarten but that was all I was offered all through college where I graduated with honors without difficulty. I had not grown up with any awareness of accommodations; I was totally functioning as a hearing person until things changed after college with my right ear.

There are environmental influences as well because when I was in my late teens and exposed to my first and last loud rock concert, I could not hear for a week. Then when I was pregnant in my twenties, my only hearing ear suddenly dropped to absolutely nothing for four months. After my daughter was born and a serious round of steroids, it came back to the severe loss level where it has remained to this day. Knock wood. I like people to sit on my good side if I want to hear them. When with someone who has the same good side such as my sister, we automatically end up practically tripping over one another trying to get on the "right" side of each other while walking. I love to review all seating arrangements at tables and in cars. Using cell phones is occasionally a problem and I prefer captioned phones for cold calls. I am a retired soccer mom and active grandmother who manages rental property so I depend on volume amplified phones, texting and email extensively.

My current latest and greatest device is my Oticon digital hearing aid with RIC-receiver in canal and the Bluetooth connectivity. I have used the trial clause for different hearing aids and struggled with trying a new brand but once I adapted with my patient audiologist's help, I was convinced. I was disappointed when I discovered at a most inopportune time that the receiver portion needs to be replaced every year or so but have since adjusted by purchasing a spare that can be snapped on. When I travel, I carry it with me. The Bluetooth capability is icing on the cake and makes hearing on my cell phone infinitely easier. A bonus is that music sounds clearer than it has in years--of course always at a safely reduced volume. Visual or shaking smoke alarms for those of us who need them must also not be neglected in my opinion.

Just like so many things in life, the more you of yourself that you give to an organization like HLAA, the more you will receive. So, please join your local HLAA chapter and join the national organization to receive the excellent bi-monthly publication, Hearing Loss. I am also a huge fan of the services of the KY Commission on Deaf and Hard of Hearing. This state agency provides telecommunication devices under the TAP program among a long list of other services. I further recommend signing up for the free Hearing Health Magazine from the Deafness Research Foundation which focuses on

helpful information as well as on research for potential cures for hearing loss.

To those forming new chapters, I recall a guideline early on that everyone should have a specific job so that everyone pitches in and things go smoothly. If a person feels the group is meeting his or her needs, then they will hopefully be inspired to become involved as a means of giving back to the group. Comradery and humor makes the time we spend together enjoyable so after many meetings we try to visit a nearby restaurant. Occasionally, there are informal dinners which are very popular because we all share the same struggles to communicate.

We rely on individual strengths as well as moving beyond our own comfort zones to address the needs of our group. Many dedicated leaders have come before us at the national and local level. We are so very fortunate to have Ron and Jean Haynes in KY who are working on our regional conference as well as organizing multiple chapters. Some people bring refreshments, or send notices to the newspaper or have learned how to keep up the website. It is not easy to build a strong group as much patience and time are needed. Different people are here for different reasons and enjoying the friendships I have made along with advocating keeps me learning and engaged. The membership has opportunity and responsibility to be part of solutions to make life increasingly more livable to others who live with hearing loss in our community and who are isolated from needed resources. That's why we are happily plugging away.