

Something Extraordinary Has Happened!...And It's All About the *People*

By Julie Olson

The organization we know today as the Hearing Loss Association of America. (HLAA) had humble beginnings. It started in 1979 in the family room of a home with someone's personal finances and support system consisting of family and close friends. That person was Howard E. "Rocky" Stone. Today his vision has grown into a movement with a remarkable following and mission. Rocky often said, "Something extraordinary has happened!"

It has. It is still happening, and it is up to us to keep it happening.

From the beginning, the organization focused on PEOPLE as human beings who had many traits and talents; hearing loss being only one of them. Rocky encouraged us to accept our "invisible condition," but not let it define us. He recognized that many hard of hearing people felt socially isolated and lived with a kind of loneliness they found difficult to explain to others. Further, they didn't know how to help themselves, much less tell others how to help them. We were stuck in a society that paid little attention to people with partial deafness.

Let's Get That Data Right!

In the early 1980s, the only data on hearing loss was sketchy at best. It assumed there were fewer than 10 million "deaf Americans." Deafness was defined broadly to include anyone with hearing loss, while research programs and agencies focused on the tiny minority within the deaf population who were culturally Deaf; users of manual communication. Thus, the prevailing attitude among agencies that worked with deaf people was "Just learn sign language and all will be well." Today valid data shows there are upwards of 48 million Americans with hearing loss, while



At the first SHHH Convention in Chicago in 1984, from left: Katie Webber, Rocky Stone, and Julie Olson. This year HLAA will hold its 30th convention in St. Louis, June 25-28. See page 27.

Julie Olson received the Rocky Stone Humanitarian Award from Founder Rocky Stone in 2000.



The author with Sam Trychin, Ph.D. (left) and Mark Ross, Ph.D., at last year's HLAA Convention 2014 in Austin, Texas.

those who are Deaf remain a tiny minority within the larger population.

SHHH brought attention to people who are hard of hearing for the first time as it separated the statistics and forced lawmakers, academia, business, media and researchers to become aware of the existence and unique needs of this huge majority within the “hearing impaired” population, the term used back then, who had never been considered seriously before. In the process, SHHH mobilized a population that many said could not be mobilized.

As HLAA reflects on its humble beginnings and achievements of the past 35 years, we realize how many changes our “uniquely difficult to organize population” takes for granted today. These astonishing achievements didn't happen in a vacuum. It took many dedicated and generous people giving personal resources of time, energy and finances to make so many good things happen. We have much to be thankful for. As we continue to want more, and expect HLAA to make more happen, we must face the reality that this kind of positive change happens only when people who want or need change get involved.

Grassroots Growth Begins with Chapters

Chapters have been central to our organization since the first chapter formed in Gainesville, Georgia in 1980 followed by 60 more chapters in the next two years. Many more followed. People heard about SHHH and got excited. According to Joan Kleinrock, the first national chapter development coordinator, “Our founder realized that if the quality of life for hard of hearing people was to change, ‘we’, the people with the problem would have to unite to make it happen,” thus, the formation of chapters would educate the PEOPLE, and create awareness of the existence of the organization. Chapters continue to be the life blood of HLAA today.

Rocky's vision was about people with hearing loss reaching out to other

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people with hearing loss. Self-help through mutual support had been documented as a healing factor for other groups of people with common experiences. SHHH needed PEOPLE with hearing loss who were willing to learn, be assertive enough to speak up about what they had learned, and share that information with others who needed it. Chapters would develop in that environment. Once a base was established, the organization could and would advocate for better laws and opportunities. It has.

PEOPLE who found SHHH, found each other. We were amazed at the therapeutic value of meeting others like us, who understood us and validated feelings that most of us had kept buried for years. Through SHHH, we found a second family that understood our fears, frustrations and reasons for behaving certain ways. Affiliation with SHHH empowered us and gave us hope for happier healthier lives. Many made helping others their personal mission.

SHHHaring Help, Hope and Happiness

There was and remains no better place to experience and share SHHH/HLAA enthusiasm and excitement than at a national convention where people with hearing loss from all over the nation come together to share, learn and socialize. It was a turning point for the organization in 1984 when it held its first national convention. Three hundred hard of hearing people gathered in Chicago to experience “Sharing Help, Hope & Happiness.” I was one of them, and that experience changed my life.

Those who were there will remember an exhausting three-day event with little sleep because there was too much to learn to waste time sleeping! People from all parts of the country got together for the first time to talk openly about hearing loss. Some who had started experimenting with technology wanted to share what they knew with others who had never heard of it before. The experience was electrifying, and we learned plenty! Audio loops, now called hearing loops, were there at the beginning! They were primitive, hand-built devices with huge batteries, but they worked for those who had “telephone switches” [telecoils] in their hearing aids. We were amazed. This gave many of us the hope that had been denied us by medical professionals who insisted that nothing could be done to help people with ‘nerve deafness’ [sensorineural hearing loss].

We started believing in the future. We realized then, how important it was to help make this organization grow. It planted seeds of motivation that affected the entire country. Some were elected to the first elected national board of SHHH at that convention, and did so at our own expense. We knew then, that this organization was worth that support because it could change lives if it grew. It has.

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Annual conventions have been held since 1986. Each provides a unique opportunity to learn; to experience emerging technologies, and share our experiences and concerns with others who understand us. Conventions provide a forum for discussion in a hearing loss-friendly environment that includes communication access of all kinds. SHHH (now HLAA) is a membership organization that belongs to

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its PEOPLE. Those people, via an elected national Board speak loudly on many issues.

At conventions, members can share ideas and ask questions. One of the first questions that needed an answer was, "Who exactly are we?" We knew we didn't hear well. We knew we were not 'deaf,' and we knew we wanted to remain in the hearing mainstream where the large majority of us grew up, were educated, married, worked, lived, and socialized; albeit with difficulty. While some of our needs overlapped with the deaf population we knew, more of what we needed and wanted was unique. We realized it was vital to recognize that people who considered themselves hard of hearing were a constituency of their own. Once we had defined ourselves, we were able to move forward.

Defining the Mission and Setting Policy

In the mid-1990s the SHHH Board of Trustees clarified the mission of the organization, and challenged the organization as a whole to be more forthright about whom we were. Mark Ross, Ph.D., a respected audiologist and member of the Board, was asked to address specific issues of concern through a series of policy papers. We were confronted, then, with culturally Deaf groups whose interests did not mesh with ours.

For example, our PEOPLE were intrigued and excited about the potential of cochlear implants, while Deaf groups felt extremely threatened by them. While we respected the rights of Deaf groups to their own beliefs, which were receiving a lot of media attention, we knew we had to take a position on these difficult issues. As a group, our population has been solidly in favor of technology and medical intervention that can help people with hearing loss of

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all ages to remain in the hearing mainstream. Those early policy papers still define the HLAA philosophy today, and more have been added. They can be found on hearingloss.org. All HLAA leaders should take time to read them.

In 1988, this organization strongly supported the development and establishment of the National Institute on Deafness and other Communication Disorders (NIDCD) within the National Institutes of Health (NIH). NIDCD expanded research on communication disorders of all kinds. SHHH was involved when the Americans with Disabilities Act was being proposed and written, and was included in an advisory capacity. Had the hard of hearing population not been defined clearly by then, "communication access" would have not have included hearing assistive technologies. Thankfully, your organization was there.

Choices, Challenges and Changes

Other milestones have changed the organization's landscape. As early as 1993, SHHH recognized the potential value of online communication and the future importance of the World Wide Web. The telephone industry was rapidly changing. First, it was about cordless landline phones that were becoming popular, but were not compatible with hearing aids

because the built-in component that connected them to our hearing aids via telecoils was being eliminated in new phones. SHHH educated lawmakers and manufacturers on the need to retain this compatibility. Before long, the focus was on cell phones.

Our organization has stayed on top of technology advances. Hearing aid compatibility became a mantra among the tech gurus within HLAA. Remaining connected was vital and efforts to remain connected have taken an abundant amount of energy from the national staff, Board, and leaders across the country in states and chapters. But we have prevailed. As general technology continues to advance, there will always be challenges to keep our population connected! Advocacy! Education! PEOPLE!

During these years, and still today, hearing aid miniaturization by manufacturers, and the promise of invisible hearing aids had led to the demise of the hearing aid component, the telecoil, that connects us to the assistive technologies we lobbied so hard for and depend on. We have a foot in the door today that has helped keep telecoils in many hearing aids. This will continue to present challenges that require advocacy, education and information sharing.

Unfortunately, many hearing aid dispensers do not activate the telecoils in the hearing instruments they sell. They do not explain their value, thus they are devalued. When they are not being used, they become unnecessary in the minds of the people who provide them. The hearing loop technology that many of us depend on today would not be an option if our organization and its members had not spent resources pushing for the inclusion of telecoils in hearing aids and cochlear implants.

Strategic Moves to Create Awareness

By the turn of the century, SHHH and its PEOPLE had become more

aware of the power of the Internet. A website had been established, but it was difficult to find. It became apparent that a name that included the words "hearing loss" would provide greater visibility for the organization via Internet search engines. In 2005 the Board made the decision that SHHH would become the Hearing Loss Association of America (HLAA). The official name change took place the following year.

The Walk4Hearing, started in 2006, has grown exponentially with Walks taking place all over the country. The fundraising potential of this event has made it possible for HLAA to continue the work it does for you and fund programs in local communities where Walks are held. The Walk4Hearing has also given HLAA visibility and an educational platform to share information about the organization and hearing loss with the general public.

Recently, HLAA has launched campaigns to "Make Hearing Aids More Affordable," and the "Consumer Technology Initiative." HLAA staff remains busy on Capitol Hill advocating on our behalf for accessible telecommunications, quality captioning, opposition to taxes on hearing devices, educational programs for children with hearing loss and much more. HLAA works hard, in many different ways, on many issues to *make hearing loss an issue of national concern.*

Over 35 short years "Something truly extraordinary has happened"! The tiny organization that was once discounted, is now known as "The Nation's Voice for People with Hearing Loss!" This has happened through information sharing, education, advocacy and peer support. It has happened because of a small, but dedicated staff and thousands of motivated volunteers who are involved at all levels. It succeeds because PEOPLE reach out to other people with hearing loss at the grassroots level and encourage them to become members of HLAA. It succeeds because

PEOPLE care enough to share what they have learned through HLAA with others. That's what it's all about!

Happy 35th Birthday HLAA!
You SHHHure have touched lives!
Thank you. **HLM**

Julie M. Olson MS, a past president (1995-1996) of the HLAA Board of Trustees, was elected to the Board in 1984, and served for 14 years. While on the Board, she was involved in several committees, including executive, state development, awards, and strategic

planning. Julie holds a baccalaureate degree in education and a master's in human services. She was involved in founding HLAA Fox Valley Chapter (Appleton WI) and HLAA-Wisconsin, and remains involved as state webmaster and newsletter editor for both the state and chapter affiliates. She has also chaired four conferences for HLAA in Wisconsin. Julie is currently the Spotlight on Chapters editor, a section on www.hearingloss.org that highlights the great work of chapters. She can be reached at julieo@athenet.net.



St. Louis Tours Announced

Plan to arrive early and stay late to take advantage of these fabulous tours arranged by MAC Meetings and Events. There will be two separate tours on Wednesday, June 24 and two different tours during the day on Sunday, June 28; a special tour Sunday evening will be to the Missouri Botanical Gardens for the Chinese Lantern Festival.

To view the details for each tour and to purchase a ticket, go to bit.ly/STLtours.

