



HLAA State and Chapter News

“Greater help comes from being part of a Chapter.” – Rocky Stone

By Julie M. Olson

HLAA Fox Valley Chapter Brings HOPE to Its Members

“We are people who do not hear well. We tend, increasingly, to be isolated. The existing pattern of community life lacks both means of communication and institutions for us to solve our special problems and live normal lives. For too long, too many of us have accepted a loneliness we are unable to explain to our friends or even to our families.

“We do not believe this situation is inevitable. We believe we can help one another, be helped and live active, healthy lives. We need to show each other, our relatives and friends, how.

“We believe that joy in sharing; strength in association; empathy and fellowship with peers; and a chance to help others who are in the same situation is a way to begin.”

Many of our organization’s long-time members will recognize these words; others might not, although they will probably feel a close, personal identity with them. These words constitute the Preamble to the original Constitution of Self Help for Hard of Hearing People, Inc. (SHHH) from 1979, the year the organization was founded. The name was changed to Hearing Loss Association of America (HLAA) in 2006.

Those words came to mind when I was inspired to share information on a recent project undertaken by the HLAA Fox Valley Chapter in

Appleton, Wisconsin. They are the very words that encouraged me to become involved in this organization more than 33 years ago.

We have seen many amazing changes in three decades, but some things don’t change. Hearing loss, particularly adult-onset, changes lives. For some, a well-fit hearing aid might be all that is needed, but for others it’s far more complex and personal.

In the early days of the organization we first came together at the grassroots level to support one another. In time we gained enough knowledge and confidence to become advocates for the development of better technologies, medical research, legislation, and more. We experimented with hearing assistive technologies that no one knew existed, and we watched many of our peers become test subjects for cochlear implants. In spite of stigmas, many of which remain today, we went public with our invisible disability. Today, while we receive the benefits of the sacrifices our Founder Rocky Stone and early members made in time, energy, and personal resources, it’s easy to forget this started and evolved because of peer support.

The HLAA Fox Valley Chapter, the first chapter in Wisconsin, was chartered in 1984. Like most chapters, attendance has waxed and waned. Leaders have come and gone. New people come regularly; some return, but many do not. In a recent effort to grow the chapter, we started asking new attendees what they came for and whether or not they would return. We discovered that something was missing,

In spite of the excellent programs we have at chapter meetings, we learned that new people were not getting the information they needed to feel better about themselves. Some said they felt uncomfortable in the large group. Further analyzed, the reason for that was that they were not getting their basic questions answered. Several said they found it difficult to talk to the people whom they wanted to ask questions of. Too many left the meeting feeling they had not gained anything.

We all know that hearing loss makes it difficult to communicate in a group full of other talkers; that one-on-one conversations work best. How difficult that is following a chapter meeting and program is a phenomenon that only a person with hearing loss can fully understand. Waiting for that one-on-one opportunity can be futile when everyone else has the same desire, and the “old timers” are anxious to leave because they have done their job of organizing the meeting. These new people needed more time, and they needed it from, and with, one another.

While our seasoned members were interested in learning more about advanced technologies and options available to them, the new people wanted to talk about their personal experiences. They needed support from others who understood their frustrations. Once they realized they were not alone, they wanted to talk about it. Peer support is basic and bonding.

When long-time members are asked why they keep coming back, a common response is, “Once I learned

I wasn't alone, I became hopeful about living better with hearing loss."

Last year, Nancy and Dave Gilbertson, new members who helped identify and clarify this "missing link" based on Nancy's personal experiences, offered to help develop a pre-meeting discussion group. They decided to call the group "HOPE," which stands for "Hearing Other People's Experiences," and that is exactly what goes on for an hour preceding each chapter meeting. No one knew if people would come at 5:30 in the evening, but HOPE attendance has grown. People come regularly, and have started bringing friends. Most remain for the regular 7 p.m. chapter meeting and program. We are seeing enthusiasm for HLAA and an increase in national membership within the chapter.

HOPE is giving people *hope*. Sometimes the tears flow when someone realizes for the first time that another person completely understands their feelings. There are the "a-ha" moments when someone discovers they can hear with the hearing loop in our meeting room. Loop receivers, which have been donated by members, are available for those without a telecoil. CART is also provided at our regular meetings. Those who stay have learned that attending a group meeting need not be an exercise in futility. People are becoming believers who reach out to share with others.

The HLAA Fox Valley Chapter is alive and well. Thanks to HOPE, it is healthier now than ever before. We hope other chapters will consider a HOPE group. When we make the effort, and provide an opportunity to listen to people who are struggling with hearing loss, it matters. Self help, which generates from peer support, remains central to building effective chapters.

That original SHHH Preamble is as meaningful today as it was the day it was written. **HLM**

The HLAA Fox Valley Chapter's HOPE group gives new members much-needed peer support to help them realize they are not alone in their hearing loss journey.



Julie M. Olson, a past president (1994-1996) 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 the HLAA Fox Valley Chapter in Appleton, Wisconsin and the HLAA Wisconsin State Association, and remains involved

as newsletter editor for both the state and chapter affiliates. She has also chaired four HLAA Wisconsin State Association conferences. Julie is currently the Spotlight on Chapters editor, a section on hearingloss.org that highlights the great work of chapters. She can be reached at julieo@athenet.net.



Finding Support in HLAA Chapters

"It is on the local level that help is most effective. Personal interaction, the pleasure of being with other people—particularly people who understand your situation—the re-establishment of confidence, shared projects, creative input, accomplishment, dignity restored—these are the things that happen in chapters."

—HLAA Founder Rocky Stone, excerpted from *An Invisible Condition*

HLAA Chapters provide strategies and support that are modeled after Rocky Stone's self-help philosophy. They offer emotional support, camaraderie, tips and techniques for living with hearing loss, and technical information about hearing assistive devices. Chapters meet regularly with speakers and discussions on all kinds of topics such as hearing aids, assistive listening devices, TV captioning, cochlear implants, how to communicate with your spouse and family members, hearing in public places and meetings, coping at work, and much more.

Hearing loss is a daily challenge. Chapters are a place where it's okay not to hear. You will be surrounded by others just like you—others who know what it's like to live with hearing loss and who truly understand your situation. Remember, you do not have to hide your hearing loss. You do not have to face hearing loss alone.

Consider joining an HLAA Chapter today! For more information about chapters or to find one near you go to hearingloss.org>Support>State Orgs and Chapters, or contact Valerie Stafford-Mallis, director of chapter development at vstafford-mallis@hearingloss.org.