

Hearing Loss Association of America

July/August 2017

hearingloss.org

Hearing Loss Magazine

“Greater help
comes from being
part of a chapter.”
—Rocky Stone



HLAA CHAPTERS

We're All
On This
Journey
Together

On the Cover

We really are on this journey together. Joan Kleinrock, HLAA's very first national chapter coordinator, said it best, "Picture a wagon wheel from the Old West, with the hub of the wheel being the national office and the spokes of the wheel the local chapters. The wheel will not turn without the hub and spokes working together—supporting each other." (Read more about Joan's own journey in *Those Were the Days* on page 16.)

Joan's analogy couldn't be more relevant. Every day, we embark on a journey to spread knowledge, provide resources and raise awareness of hearing loss. Our continued work and shared efforts get the wheels turning, and with each new accomplishment, both locally and nationally, we gain momentum toward reaching our final destination and goal.

For this issue's cover we invited a few chapters near the national office in Bethesda, Maryland to join HLAA National Chapter Coordinator Erin Mirante on a little journey of our own. The sun was shining on the warm late spring day so we put the top down and got rolling. We asked our fellow travelers Russ Misheloff, Rachel Stevens and Veronica Davila Steele to share a few thoughts about their chapter's journey. Now, won't you join us?

Chapter: District of Columbia

Travelers: Russ Misheloff, chapter president and founder; Rachel Stevens, outreach chair

Founded: 2010

Why did you see the need for a chapter in your area?

Russ: My need for a chapter (or more correctly, a community from which to learn) was personal. I needed help. But it very quickly became apparent to me that many others were in the same boat. If the prevalence of hearing loss in D.C. and the surrounding area is about the same as it is nationwide, which is likely, there could be more than 100,000 people locally who are in need of support. Chances are few of them are getting the help they need to function and thrive in the wider hearing world. For many this has unfortunate health and quality-of-life implications. So our goal is to reach out to as many people as we can.

What made you want to join the chapter?

Rachel: I moved to the area when I was 25 and I had never met someone my age with hearing loss. Everyone was so friendly and welcoming at the first chapter meeting I went to that I immediately wanted to get involved. Now I've made several friends through the chapter who share the challenges that come with hearing loss and we are there to support each other through those challenges.

What accomplishment are you most proud of the chapter for?

Through our programs, internet and social media we have expanded our reach and are now frequently called upon to provide support to current and prospective members and to partner with other service organizations. This is a source of pride to us.

Chapter: Prince George's County, Maryland

Traveler: Veronica Davila Steele, chapter president

Founded: 2016

How has the chapter become more involved in the community?

We have reached out to first responders in local police and fire departments and to all of the districts in Prince George's County. We have been participating in Coffee Club and Community Roundtable meetings, which are monthly get-togethers held by each district where members of the community can network and discuss various topics. They are attended by many community leaders and groups such as civic associations and homeowner's associations (HOAs). These meetings have also led us to participate in several health fairs held by various county agencies and also events held by elected officials.

As a new chapter, have you received any assistance in reaching out to people?

The Maryland state chapter coordinator, Margaret Widner-Kolberg, has been instrumental in guiding us in our outreach efforts. Being a new chapter we were pretty green in knowing how to begin the process of educating and sharing vital information to people with hearing loss in Prince George's County. We've also been fortunate to work with Drs. Henry and Medwetsky from Gallaudet University who brought their knowledge and expertise to our presentations.

How does the chapter raise money?

This will be our task in the coming year! Interested in learning how other chapters are addressing this.

You can read the full interviews on our **Chapter Spotlight** page at hearingloss.org/content/spotlight.



Rachel Stevens



Russ Misheloff



Veronica Davila Steele and Somalia ("Sammie")



© Cindy Dyer

“ Hope flourishes in community, not isolation. That is why the concept of chapters at the local level is so important. ”

—Rocky Stone, HLAA founder

We're All On This Journey Together

Self-help does not mean that you have to be alone. While Rocky Stone believed in advocating for oneself, he also knew that help and support come from being around those who understand what you're going through. HLAA has nearly 150 chapters and state organizations nationwide, all made up of volunteers who dedicate their time, effort, and energy to further Rocky's vision.

Since joining HLAA last November as national chapter coordinator, I've had the honor of learning and experiencing firsthand just what makes our chapters so vital to the organization. In so many ways, we function as a team. In the national office I am here for all of our chapter volunteers should they need any help, but it is encouraging to see that many chapters are flourishing, with their leadership teams able to work through the questions and challenges which inevitably arise.

My goal is not only to provide the chapters with the resources and assistance they need, but also to be a cheerleader for them and observe what they do best! Where would we be without the grassroots efforts of chapters across the nation to raise awareness of hearing loss by sharing their passion for HLAA's mission of providing information, education, support, and advocacy?

The efforts of the chapters on the local level are integral to the mission of the whole organization. From advocating for hearing loops in theaters, houses of worship and other public venues, to exhibiting at expos and health fairs, to offering a safe space for individuals where they can feel comfortable sharing their hearing loss stories and issues, our chapters do it all!

HLAA Chapters provide members and non-members alike with valuable and tangible benefits. It is the feeling a new member has when they leave their

very first meeting after having been warmly welcomed and supported throughout; the excitement in seeing a movie that everyone is talking about in a hearing-accessible theater; or the bonds that develop between people who face the same hearing loss challenges on a daily basis.

All of this success can be attributed to the ongoing efforts and initiatives of chapters within their own communities. The effects that our chapters have are lasting, and certainly deserve recognition. So to our chapters, state organizations and state chapter coordinators, we thank you for your willingness and passion to make a difference in the lives of people with hearing loss.

We want to take this opportunity to share just a few of the many stories of chapters who have found success through initiatives and efforts in their local communities. Whether you get some inspiration or find that you can relate to their story, we hope you enjoy learning what these chapters are doing to help them thrive!

HATs Off to the Long Beach/Lakewood Chapter

Founded in 2009 by Chapter Member Dr. Bill Busch, the Long Beach/Lakewood (California) Chapter's HAT (Hearing Assistive Technology) Committee holds numerous outreach events that have helped thousands of people with hearing loss live more independently.

Visitors to HAT demos may see and try more than 50 technology devices that help with everyday hearing issues. Vibrating alarm clocks, fire/smoke alarms with flashing lights, captioned and amplified phones, personal amplifiers for noisy environments and devices to hear TV and

continued on page 12

HAT Committee Members (l to r) Katie Wright, Gail Morrison, Craig Bowlby, Ilga Dravnieks, Van Vonburg and Dr. Bill Busch



WE'RE ALL ON THIS JOURNEY TOGETHER

continued from page 11

music better are just a few of the products you will find at the demos. While we don't sell any items there we do offer information on where someone can purchase them.

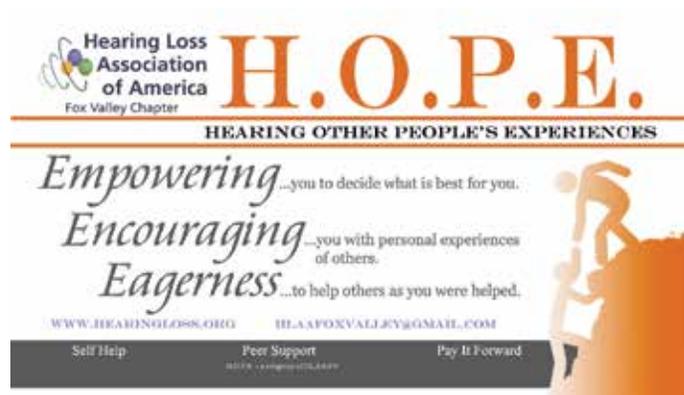
The HAT Committee was recently recognized for its efforts by the Disabled Resources Center (DRC), a local nonprofit organization that helps people with disabilities live more independently. The DRC presented the HAT Committee with the Community Service Award for "volunteering in the community to help people with hearing loss live more independently" at their annual awards dinner in June. HAT Committee members honored were Dr. Bill Busch, Herb Balkind, Peg Heglund, Helen Bologna, Ilga Dravnieks, Dr. Doug Green, George Costello, Bonnie Strutin, Craig Bowlby, Van Vonburg, Gail Morrison, Ron and Elfriede MacIver, Katie Wright, and Don Hachiya.

HAT demos are held on the third Friday of every month except during June, July, and August from 10 a.m. to noon at the Weingart Senior Center, 5220 Oliva Avenue, Lakewood, California. If you plan on being in the area make sure you stop by!

Submitted by Gail Morrison, HLAACalifornia State Association Board of Trustees vice president.

The HLAACalifornia State Chapter is Giving H.O.P.E. to Its Members

It doesn't matter if we have lived with hearing loss for years, or have acquired it recently, most of us have lived only within the hearing world. Most people we know do not have a hearing loss so it is impossible for them to understand our frustrations and loneliness. That is why the HLAACalifornia State



Business cards are handed out by chapter leaders and regular attendees who spread the word of H.O.P.E. at local churches, gyms, and other public places.

Fox Valley Chapter in Appleton, Wisconsin is offering H.O.P.E. to our members.

H.O.P.E.—Hearing Other People's Experiences—is an opportunity for people to come together in an informal circle of friendship, supported by a hearing loop so all can hear. Everyone is encouraged to express their concerns and share their experiences. We work together as a team, helping and supporting one another. It's about connecting with one another; it's about feeling you belong.

Thanks to generous chapter sponsors and members, we have also created a H.O.P.E. Chest containing various assistive listening devices. Technology can be overwhelming for many people. The H.O.P.E. Chest allows people to test equipment and educate themselves to find what works for them before they buy.

Some people don't want advice, just someone who understands. So they don't feel alone, in addition to H.O.P.E. meetings a chapter email is available. We will also arrange to meet someone one-on-one if they wish. Chapter members are appreciative, and in turn, tell others about HLAACalifornia State and H.O.P.E. This has brought momentum back into our chapter and we are growing!

Here is some of the wonderful H.O.P.E. feedback we have received:

"One thing that amazes me is the willingness of those offering genuine help with no thought of payback."

"The information about hearing aids, hearing loops, and assistive hearing devices is truly a great service."

"We tell our friends of the help that is available and how HLAACalifornia State can be so instrumental in helping people with hearing loss."

"The H.O.P.E. gatherings are an integral part of the HLAACalifornia State Fox Valley Chapter, a blessing for all the members."

Submitted by Nancy Gilbertson, HLAACalifornia State Fox Valley Chapter H.O.P.E. facilitator

The Power of CART

The Plymouth, Massachusetts community was upset, angry, and frustrated because of a memo released by the U.S. Nuclear Regulatory Commission (NRC) who said that our local nuclear power plant, the Pilgrim Nuclear Power Station (said to be the third most dangerous in the nation) was continually not meeting safety guidelines. The memo suggested closure. The NRC had a community-wide meeting



NRC meeting in Plymouth with CART provided

on January 31, 2017.

Fortunately, just days earlier, I attended an empowering meeting of the HLAA Plymouth Chapter. There, I witnessed the power of CART (Communication Access Real-time Translation) and heard the inspiring words of Jonathan O’Dell, assistive technology manager for the Massachusetts Commission for the Deaf and Hard of Hearing. He gave an uplifting presentation, telling us things like we don’t have to feel sorry for ourselves or be ashamed of our hearing loss.

Three days later, on a Friday morning just days before the coming meeting, I requested CART to be provided at the meeting. With 36 hours to go, and with the involvement and assistance of the town, the state—and even the federal government—CART was made available for the meeting. This was the first time it was ever provided at a meeting such as this. If I hadn’t attended the chapter meeting, I wouldn’t have even known to ask for it.

The meeting was attended by more than 300 people and it was filled with both anxiety and tension. One of the saving graces was the skill of the CART provider. She was fantastic, and got up to speed on this new vocabulary quickly. The captioning proved to be beneficial to everyone—the public, the officials, and of course, those of us with hearing loss. It was easy to read and since it was in realtime and very accurate it could be read in the context of the thought.

Six weeks later, CART was also provided at a follow-up NRC meeting. However, this time there were some problems. The words were too large for the screen and it was difficult to comprehend the context within which they were stated. This might have been because the size of the room at this meeting was much larger than the first. Multiple screens spaced throughout the hall might have

been a solution to this problem.

In both meetings, the organizers and agencies involved showed that they were attempting to accommodate people who needed help communicating. The public, although angry, witnessed this effort. It was greatly appreciated and many people—public and officials alike—made favorable comments.

While the responsiveness of all those involved is greatly appreciated, none of this would have been possible without the Americans with Disabilities Act. We got the accommodations we needed as a result of the important protection it offers to people with disabilities.

In addition, much of the credit for making all this happen goes to Sandy Spekman, our chapter leader, who was almost single-handedly responsible for starting the Plymouth Chapter. Our chapter meetings provide us an opportunity to improve the lives of those with hearing loss.

Submitted by Irene Caldwell, HLAA and Plymouth Chapter member

Putting Policy Into Action: State Associations and Local Chapters Make it Happen

On May 10, 2017, Aging and Disability Services, a division of the Seattle Human Services Department, hosted the Care Transitions: We’re All in It Together Conference. It was a perfect example of what happens when local advocates and their allies join together to carry out the mission of HLAA. Dozens of health and human service providers in the Seattle area are now talking about hearing loss, its

continued on page 14



Chapter and state association members at the Care Transitions Conference (l to r) Cheri Perazzoli, Kelly Tremblay, Bill Wallhagen, Kimberly Parker, Cynthia Stewart, Margaret Wallhagen, Janet Primomo

WE'RE ALL ON THIS JOURNEY TOGETHER

continued from page 13

effects, accessibility, and policies to make sure people with hearing loss receive better care and support.

The conference featured an educational session about hearing loss presented by HLAA Board of Trustees Member Margaret Wallhagen, Ph.D. (who recently completed her term as chairperson of the Board of Trustees), and fellow Board Member Kelly Tremblay, Ph.D., from the University of Washington.

The HLAA Washington State Association contributed slides for the presentation, and members were available to answer questions and hand out HLAA information packets. Hearing loops and CART provided hearing access for every session, showing how people with hearing loss hear and participate fully—illustrating in real time how planners can create a hearing-friendly event.

Community-based efforts like these are how state associations and local chapters can make the national goals of HLAA become a reality. For example, the HLAA Washington State Association connects with key groups and government agencies such as the Washington State Office for the Deaf and Hard of Hearing (ODHH), the Association of Area Agencies on Aging, and the Washington State Long-Term Care Ombudsmen Program, to talk about the effects of hearing loss and to make sure hearing loss education and hearing care are part of state policies. We helped get Senate Bill 5177 passed, which requires hearing loss recognition training for long-term care workers.

To make sure hearing aids are affordable and accessible, HLAA Washington State Association is working with lawmakers, AARP Washington, and the Washington State

Senior Citizens Lobby to ensure hearing aids for adults are covered under Medicaid.

Thanks to these bridge-building efforts, the HLAA Washington State Association was able to call on local hearing access providers Darlene Pickard of Captions Northwest and Spencer Norby from HearingLoop NW at the last minute. ODHH ushered contacts through, and Conference Co-chairs Irene Stewart and Alison Boll ensured hearing loss was on the agenda.

Hearing-friendly communities start with national goals and are often realized through local “boots on the ground” member activities like these. What can your chapter or state association do to bring HLAA national goals to life in your neighborhoods?

Submitted by Cheri Perazzoli, director of advocacy, HLAA Washington State Association

Making Hearing Loss Visible One Extravaganza at a Time

The first Florida statewide Let's Make Hearing Loss Visible Extravaganza was held on April 22 at the Orlando Health Medical Center. Hosted by the HLAA Florida State Association and State Chapter Coordinator Tanya Williams, the event was designed to bring together the hearing and those with hearing loss alike for support and to encourage people to become hearing loss advocates.

Why? People of all ages with hearing loss require support and guidance in their hearing loss journey, especially from those around them who are hearing, such as spouses, partners, parents, friends, co-workers and children. Not only are they an integral part of helping someone close to



Attendees at the Let's Make Hearing Loss Visible Extravaganza could barely contain their excitement!

HLAA has nearly 150 chapters and state organizations nationwide, all made up of volunteers who dedicate their time, effort, and energy to further Rocky's vision.

them live successfully with hearing loss, they are also critical in having a broader impact and making a difference in others' lives as present and future advocates. They can help with everything from understanding effective communication, to stressing the importance of hearing protection, to assisting a family member, friend or fellow employee in need of hearing loss support and information.

The Let's Make Hearing Loss Visible Extravaganza proved to be a great success! With less than four months of planning, sponsors, speakers and volunteers came together to produce the event, which was completely hearing-accessible, offering sign language interpreters, CART and hearing loops.

The event featured an exhibit hall with a wealth of information available and two workshop rooms overflowing with people of all ages with hearing loss, as well as those with hearing. Workshop and panel topics included early steps, music therapy, the power of positive thinking, the importance of speech and mental therapy, lipreading, sign language, hearing dogs, effective communication and socializing, and cochlear implants. In addition, current and potential chapter and support group leaders and volunteers participated in an afternoon workshop with the Florida state chapter coordinator.

Thanks to the success of the Let's Make Hearing Loss Visible Extravaganza, more individuals and organizations statewide are sharing information about HLAA and offering support. In fact, Karen Adams, an anchor and producer from WJXT Channel 4 News in Jacksonville, has promoted chapter events in Florida and Georgia as well as the recent national HLAA2017 Convention! **HLM**

Submitted by Cynthia Moynihan, president of the HLAA Florida State Association



Erin Mirante is the HLAA national chapter coordinator. She can be reached at emirante@hearingloss.org.

Finding Support in HLAA Chapters

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 and feature 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 well. 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](http://hearingloss.org/support/StateOrgs) and Chapters, or contact Erin Mirante, national chapter coordinator at emirante@hearingloss.org.

