

Hearing Loss, Hearing Health, Hits the Big Time

BY BARBARA KELLEY

This year, HLAA celebrates its 40th anniversary. When Howard E. “Rocky” Stone founded our organization in 1979, living “between two worlds” with a hearing loss—not totally deaf yet not fully hearing—wasn’t front-page news. But for those who had hearing loss, dealing with it was a constant—whether it was trying to survive on the job in a hearing world, deciding whether or not to take an early retirement, or just getting by in day-to-day situations.

There was no internet. And when you went to the library, there was little in the card catalog (remember those?) on how to maximize residual hearing to stay connected and engaged in the hearing world. Yes, there was a lot of information

Positively, we’ve reached an exciting and unprecedented time for people with hearing loss and for HLAA. Given all these important initiatives, the future can only get better.

on being deaf and Deaf culture. But there was nothing that addressed the challenges of people aging into a hearing loss. And if you asked your doctor back then, you likely were met with responses like, “It’s a normal part of aging. There’s nothing you can do. Go learn sign language.”

Hearing aids were around, but the most we saw in hearing assistive technology was a lot of Rube Goldberg approaches. Telecoils were in hearing aids, but there weren’t enough loops. People could use TTYs (text telephones), but they didn’t compare to the captioned telephone service we have today, which is much more advanced and creates a quality, more natural way to use the phone. In the mid-1980s, the Food and Drug Administration (FDA) approved cochlear implants—but they were only considered an option for people with profound hearing loss. Even then, they were typically prescribed for just one ear.

Was this anyone’s fault? No. It’s just that we didn’t treat hearing loss as a primary health concern. In fact, when Medicare first began in 1966, it specifically excluded coverage of hearing aids. Why? Maybe because the medical community and policymakers didn’t consider hearing loss to be life-threatening or life-altering. But we know better now. We know that untreated hearing loss can lead to anxiety, depression, isolation, falls and cognitive decline. Untreated hearing loss can lead to people leaving their jobs in frustration. And we now have scores of studies that show that hearing loss may be tied to other chronic conditions. Undoubtedly, hearing loss is an important health issue.



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HLAA sees positive opportunity in all that's happening on the advocacy and leadership fronts. And apparently, you do too. Together, we're extending our reach from the federal level into your communities, where our local chapter and state people are serving on local boards and advocating for communication access.

It's More Than Just the ADA

The landmark Americans with Disabilities Act (ADA) of 1990 put people with disabilities on equal footing for access in public places. And we're proud to say that HLAA, with our members' input, was part of the rulemaking process for the communication access section that includes rules for technology assistance, along with sign language.

That was almost three decades ago. And certainly, the ADA was a giant step.

But it isn't enough. We need greater awareness. And we need people like you to ask for accommodations.

Let's Hang Onto *The Lancet* Report

The Lancet (lancet.com), a prestigious medical journal, published a review article last July on the state of global hearing health care and the need to improve it: "Global hearing health care: new findings and perspectives," by Blake S. Wilson, Debara L. Tucci, Michael H. Merson and Gerard M. O'Donoghue. The review article highlights the results from the most recent Global Burden of Disease (GBD) Studies—the most comprehensive worldwide observational epidemiological study to date that examines trends from 1990 to the present, according to *The Lancet*. The results indicate a growing—and now alarmingly high—burden of hearing loss, which has become a major concern for global health.

The authors of the review article go on to discuss how hearing loss reaches far beyond the ears. They point out that it's damaging to childhood development. And they say that adults with disabling hearing loss experience profound isolation and withdraw from society and

family interactions. What's more, the authors underscore the enormous economic and personal consequences of hearing loss.

Now, a new Lancet Commission is set to follow up on the report and identify ways to reduce the global burden of hearing loss, focusing on prevention, policy, technology and protection.

Truly, this is an important moment. *The Lancet* review article—along with the recommendations from the comprehensive report from the National Academies of Sciences, Engineering, and Medicine (NASEM) titled *Hearing Health Care for Adults: Priorities for Improved Access and Affordability*—are putting hearing loss on the map.

And that's good for all of us.

HLAA Is at the Table, Advocating for You

HLAA sees positive opportunity in all that's happening on the advocacy and leadership fronts. And apparently, you do too. Together, we're extending our reach from the federal level into your communities, where our local chapter and state people are serving on local boards and advocating for communication access. They're right where they need to be, pushing hard for the passage of state and local laws that address the needs of people with hearing loss.

Of significance, Debara L. Tucci, M.D., M.S., M.B.A., one of the authors of *The Lancet* review article—who also has presented at several HLAA Conventions—was appointed on May 2, 2019, as the new director of the National Institute on Deafness and Other Communication Disorders (NIDCD) of the National Institutes of Health (NIH). She also served on the NASEM committee and is well-versed in consumer issues.



HLAA Director of Public Policy Lise Hamlin and HLAA Executive Director Barbara Kelley with FCC Commissioner Jessica Rosenworcel.

HLAA Board Chair Richard Einhorn and I serve on the NIDCD Advisory Committee. HLAA Board Member Katherine Bouton will serve on the Lancet Commission on Global Hearing Health that I mentioned above. Lise Hamlin, our director of public policy, continues as an appointed member of the Disability Advisory Committee (DAC) of the Federal Communications Commission (FCC) that tackles issues like captioning, hearing-aid-compatible cellphones, and captioned telephone service—where she’s served as co-chair in the past. She further advocates for people with hearing loss by serving on many coalitions and advisory boards that affect how you live your life with hearing loss. What’s more, HLAA often takes the lead on filing public comments.

In addition, the FDA appointed HLAA Medical Advisor Frank Lin, M.D., Ph.D., to serve on its Ear, Nose and Throat Devices Panel (ENTDP). Currently, HLAA and its constituents are particularly focused on hearing aids with telecoils and the upcoming rules for over-the-counter hearing devices mandated by the Over-the-Counter Hearing Aid Act of 2017, a recommendation of the NASEM report.

Since last year and concluding this past March, I served as the U.S. chair to the Consumer and Professional Advocacy Committee supporting the Delphi Cochlear Consensus Process—an industry-wide effort that includes manufacturers, advocates, surgeons and audiologists—to

begin the process of creating a standard of care for people with severe-to-profound hearing loss and cochlear implantation.

Also noteworthy is our activity pertaining to current legislation on Capitol Hill. There are three Medicare expansion bills in the House of Representatives that include coverage for hearing aids. These are in the very early stages and will need Senate support before they can move, but we’ve met with Capitol Hill staff to make sure HLAA and our constituents are heard. As things currently stand, cochlear implants are covered, but the road to

getting Medicare to cover hearing aids will be a long one. We’ll need you to be with us along the way.

Positively, we’ve reached an exciting and unprecedented time for people with hearing loss and for HLAA. Given all these important initiatives, the future can only get better.

Rest assured, HLAA will be at every table we can—advocating for you. **HL**

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