A CONSUMER’S PERSPECTIVE

Paying It Forward to Help All Children with Hearing Loss Have a Chance to Succeed  Paige Stringer, MA, MPH

The course of our lives is greatly affected by where we are born and the opportunities afforded to us. I was born with a severe to profound hearing loss that was identified when I was 11 months old in an era before newborn hearing screening programs. I was immediately fit with hearing aids and provided with the professional expertise as a baby and toddler that I needed to learn to listen and speak.

After attending an early intervention program for children who were deaf or hard of hearing, I joined my hearing peers in mainstream schools starting at kindergarten. I earned a full tennis scholarship to the University of Washington and, after graduation, embarked on a career in marketing and business development that included positions at The Clorox Company and Amazon. I later obtained a Master’s degree from the University of San Francisco and a Master’s of Public Health, Global Health degree from the University of Washington. I know that my academic and career successes and the personal fulfillment I enjoyed along the way would not have been possible without the resources and support that I received in my earliest years.

While I was a candidate for a cochlear implant, I did not make the leap to a CI until just seven years ago as an adult. I felt I was doing well enough with hearing aids and, after a lifetime of wearing them, certainly had figured out how to adapt to the world with less than optimal hearing. To trade the hearing that I was familiar with for something different, even if it was projected to be much better than my current reality, was not an easy decision. I faced the inevitable when it came time for me to upgrade my hearing aids and I was having a difficult time finding a new pair that worked for me. It was clear that another solution was warranted. I am very grateful to friends, family and colleagues who were patient and supported me in this process.

When my CI was turned on, my initial reaction was relief that the sound I was hearing did not seem to be any worse than what I had experienced with hearing aids. In the months and years since activation of my CI, my appreciation for this amazing technology has grown tremendously. All the sounds of life have become more accessible, louder, and clearer. My hearing with the CI continues to progress bit by bit over time and I am hearing better now than I ever have. I joke to family and friends with normal hearing that while their hearing may disintegrate as they get older, mine may actually get better as I age.

My personal experience with hearing loss is in stark contrast with my work experience in developing countries as the Founder and Executive Director of the Global Foundation for Children with Hearing Loss (GFCHL).

In 2008, I had the opportunity to volunteer at a school for the deaf in Vietnam. My task was to support the Vietnamese teachers as they taught English to the children. However, it quickly became clear that my mandate for being there would be much larger. Many of the professionals I met in Vietnam in 2008 had never encountered an adult with my degree of hearing loss who could communicate through spoken language, and they marveled at my ability to do so. At one point, they asked me politely to undergo a hearing test to verify my hearing loss. It was the first time in my life that I was happy to have such a horrible audiogram.

My ability to listen and speak in spite of a significant hearing loss is not unique in the more developed countries of the world. However, it was unusual in Vietnam at that time. Hope seemed to be sparked among these professionals that perhaps their commitment to figuring out how to help their youngest children with hearing loss develop listening and spoken language skills could eventually result in positive outcomes.

During my time there and in subsequent visits, the Vietnamese provided me with a broad perspective of the challenges that their professionals and families faced in helping their children with hearing loss. There was no hearing screening taking place and few early intervention programs were available. The cost of hearing technology was prohibitive for families. Audiology services were limited and expertise in speech pathology and auditory-verbal therapy was just starting to develop. The universities did not offer degree programs in these topics. Medical and educational professionals who worked specifically with children with hearing loss were hungry for more knowledge to better prepare themselves for their work.

An Asian proverb states, “one generation plants the trees, another gets continued on page 13
the shade.” As I increased my understanding about the detrimental impact that limited expertise and support services were having on the lives of hundreds of deaf and hard of hearing children in Vietnam—as in many developing countries—I felt the impact of those gaps very personally. I understood deeply how different my life would have been had I not received the services I did when I was young. I felt empathy for these children and was compelled to help by paying forward the benefits that were provided to me. I founded the Global Foundation for Children with Hearing Loss (GFCHL) to help children in developing countries access the early identification, hearing technology, and professional expertise they need to learn to listen and speak and be able to achieve whatever goals they have for their lives.

The GFCHL is an international nonprofit organization that provides training programs in pediatric audiology and auditory-verbal practice to local medical and educational professionals in developing countries who work with children with CIs and hearing aids and their families. Our training team is comprised of professionals in audiology and auditory-verbal practice from several countries who help to develop the GFCHL training curriculum and customize the material to accommodate the culture and language of the country in which we are working.

They also travel to the countries where we have programs to contribute their time and expertise to the training effort. Participants in our training programs are prepared to train others in their own countries to make the benefits exponential and sustainable. The GFCHL also works to raise awareness with government officials, local practitioners, and families about the continuum of care from early identification to habilitation support that is required for young children with hearing loss to learn to listen and speak. We help our local partners address gaps in services across hearing health care and early intervention.

Our efforts in Vietnam over the past decade have contributed to a solid foundation of knowledge and professional expertise that young children who are deaf or hard of hearing in that country. This strong foundation has helped the government become aware that children with hearing loss can learn to listen and speak. Today, there are many early intervention programs and audiology services for children with hearing loss in Vietnam. Children with cochlear implants and hearing aids attending mainstream schools are no longer the novelty that they were a decade ago. Perhaps in the future a governmental program will be established in Vietnam to provide families with financial support to help offset the cost of hearing technology and habilitation.

Before the GFCHL began its work in Mongolia in 2016, the government started providing subsidized CIs to families of children with hearing loss who would benefit from the technology. The Mongolian government also passed a mandate to implement a national newborn hearing screening program. However, at the time there was just one hospital in Mongolia that had the equipment to do the testing. There was also an opportunity to strengthen their audiology and auditory-verbal therapy services. The GFCHL helped the Mongolian government meet its mandate in the capital of Ulaanbaatar by providing hearing screening devices, a tracking system, and technical support which has resulted in about 33,000 babies to be screened for hearing loss each year. Additionally, the GFCHL initiated its training programs in audiology and auditory-verbal therapy for Mongolian medical and educational professionals in Ulaanbaatar. With the support of the government and other partners, both aspects of this program will be expanded to the rural areas of the country.

Increasingly, low resource countries are becoming aware of CIs and the potential life-changing benefits of the technology for young children with significant hearing loss. However, the focus is usually squared on the hearing technology and associated surgery alone. There is not enough emphasis on developing the continuum of care that is required for children to have successful outcomes with the technology.

We are fortunate to live in a time when cochlear implants are available. Programs such as those provided by the GFCHL help to lay the foundation of support services and expertise required to ensure that young children with hearing loss can take advantage of hearing technology to learn to listen and speak, attend mainstream schools, and reach their potential—no matter where in the world they live.