

By Barbara Liss Chertok

Raising Awareness of Hearing Loss on a Global Scale

An Interview With Ruth Warick, President of the International Federation of Hard of Hearing People

By all accounts, HLAA Convention 2016 was a great success. The event brought more than 1,500 attendees from 22 countries to our nation's capital to learn, experience new technology, and to socialize with other people with hearing loss.

However, there was a unique aspect and sure contributor to the success of this year's Convention—HLAA was honored to host the Congress of the International Federation of Hard of Hearing People (IFHOH). The IFHOH holds a Congress every four years in a different part of the world, and this is the first time it has been held in the United States.

The IFHOH is an international, non-governmental organization representing the interests of more than 300 million hard of hearing people worldwide. It is a not-for-profit, benevolent and charitable organization and has its seat in Hamburg, Germany.

In a news release from March 3, 2016, the IFHOH stated, "Over 360 million persons—five percent of the world's population—have a hearing loss and 32 million are children. Around 60 percent of childhood hearing loss could be avoided through preventive measures, and for other children, their quality of life can be improved through hearing aids, cochlear implants and support services." Hearing loss constitutes one of the largest categories of disabilities in the world.

Ruth Warick, Ph.D., was elected president of the IFHOH in 2010, and was recently re-elected to her fourth two-year term. She is one of the founding members and past president of the Canadian Hard of Hearing Association. Ruth represents the IFHOH on the International Disability Alliance (IDA) and serves as the second vice-chair. The IDA is a network of international disability organizations and works with the United Nations (U.N.) in Geneva, New York City and around the world. She is also involved in organizing a walkathon to raise money for a new building for the Western Institute of the Deaf and Hard of Hearing, a service delivery agency in Vancouver, British Columbia.

Ruth is a prolific presenter and author. Among her publications is *Hearing the Learning, A Postsecondary Handbook for Students who are Hard of Hearing*. She received her doctorate from the University of British Columbia in 2003. Her dissertation was titled *Voice Unheard: The Academic and Social Experiences of University Students who are Hard of Hearing*.

Ruth lives in Vancouver, British Columbia and can be reached at president1@ifhoh.org and ifhoh.org.

You were born with a hearing loss yet you didn't get your first hearing aid until age 11. Why the delay?

At age five my parents explored getting a hearing aid for me but were advised by our family doctor that I would become "too dependent" on one! Fortunately, nurses conducted a hearing test at my school, which led to my getting a hearing aid just prior to entering the sixth grade.

You attended mainstream schools. Was this a positive experience for you and how important do you feel this is for students with hearing loss?

It was a positive experience insofar as I was part of what the educational system offered to all students. I took French, Latin, geometry, chemistry and all of the subjects other students had the opportunity to take. I was active in extra-curricular activities such as sports and also had social networks. I felt part of the whole school.

It was not always easy, though. In my early years I struggled with hearing, with speech difficulties and the tendency to be left behind. There were no support services. I assumed that I was not very bright, but this spurred me on to work hard. I learned to study on my own and spent hours reading and writing using my father's old typewriter. I barely passed second grade but I was an "A" student by the time I graduated from eighth grade. I went on to university and pursued a love of learning by getting several degrees, including a Ph.D.

What jobs have you held and are you currently employed?

I have had an eclectic career. I started out as a newspaper reporter. I remember telling the city editor that I had a hearing loss on my third day of employment; his response was "Oh, my God!" But I ended up working there for six years.

I then moved to a university where I organized continuing education opportunities and became an assistant professor at the age of 30. From there I joined the government as head of a women's employment branch, then as a director of continuing and professional development for government employees.

In 1991, I took a different turn and started working in disability services at the University of British Columbia. I approve and arrange for the reasonable accommodations for students with all types of disabilities to enhance their post-secondary success. It is a job that still challenges, humbles and rewards me.

When was the IFHOH founded? What is its mission?

The IFHOH was founded in Stockholm in 1977. It represents the interests of hard of hearing people and their families worldwide and our purpose is to promote greater understanding of hearing loss issues and to improve access for all hard of hearing people. We provide a platform for cooperation and information exchange among members and interested parties.

We work closely with the European Federation of Hard of Hearing People and have Memorandums of Understanding regarding mutual areas of cooperation with the International Federation of Hard of Hearing Young People, the Asian Pacific Federation of the Hard of Hearing and Deafened, and the World Federation of the Deaf. Our board members live in Canada, Finland, Israel, the Netherlands, New Zealand and Uganda. We meet once or twice a year in person but otherwise meet at least monthly by using text messaging.



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The IFHOH believes that people with hearing loss have the right to an inclusive and accessible education system and should have equal opportunities to participate in post-secondary and adult education programs. How close is the IFHOH to achieving this goal?

This goal has been achieved to a considerable degree in many parts of the world where there are provisions for accommodations and laws against discrimination. However, there are many countries where the provision of education is less than optimal and hard of hearing children do not have the

support and services to learn alongside hearing children.

I am very pleased that members of the IFHOH around the world held awareness events and promoted World Hearing Day 2016 this past March. Hearing loss is an often invisible and neglected condition. For young children it is particularly important to have early detection and support services to achieve their full potential.

What are some of the highlights of the plan that was adopted by the IFHOH at its biennial general meeting at the 2016 Congress in Washington, D.C.?

At the top of the list of the Washington Declaration 2016 is advocating for quality, affordable hearing aids and for cellular phones with telecoil compatibility.

Another highlight is the work on improving captioning and speech-to-text guidelines for its provision at the U.N. and related events. We recently conducted a user survey in conjunction with the World Federation of the Deaf. The results were released at a workshop held during the HLA Convention. We will host the IFHOH Hearing Loops and Technology Conference with our German member organization from October 6-8, 2017 in Berlin. This will be the fourth hearing loop conference.

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Has the IFHOH developed any materials or workshops of particular significance recently?

The IFHOH has released a video on the Convention on the Rights of Persons with Disabilities (CRPD) and how it can be applied to uphold the rights of people with hearing loss. You can find the video on YouTube by searching “IFHOH CRPD.” The video reflects global collaboration involving participants from Denmark, Nepal, Pakistan, Slovenia and Uganda. Funding for the video was provided by the Oticon Foundation of Denmark.

We have developed a toolkit on the CRPD as well as workshops to build our capacity to use the CRPD and the U.N. sustainable development goals as instruments to address hearing loss concerns. The workshop attendees are part of a network using these instruments for change in their communities.

How does the IFHOH work together with the World Health Organization (WHO)?

The WHO staff on the Prevention of Deafness and Hearing Loss consults with us for technical advice in the development of its documents, including a hearing loss fact sheet, community-based rehabilitation guidelines and their *Childhood Hearing Loss* publication.

We promote WHO’s World Hearing Day as an important vehicle to increase awareness about our needs and to reduce the stigma of hearing loss and promote the use of supports such as hearing aids and cochlear implants.

In comparing the IFHOH with HLAA, how do they differ and how are they alike?

We differ insofar as HLAA is a U.S. organization and the IFHOH operates at the international level. We are united in our common cause to create a more hearing accessible and inclusive society and are focused on similar issues, including the use of technology to improve the lives of those with hearing loss. Both organizations are consumer and self-help driven. It is the people with hearing loss who set our agendas and lead the movement for change.

How would you say hearing loss is perceived differently in the U.S. versus in countries abroad and how is it acted upon differently in both regions?

Perceptions of hearing loss are cultural so there are bound to be differences. But what we share is a lack of understanding and awareness. The act of self-disclosure of a hearing loss takes courage because of the stigma that still exists and the sense of being marked as different from everyone else. Yet, disclosure is necessary for effective communication and use

of the resources and support services available to us to reduce the impact of hearing loss.

In the U.S., we have Medicare and Medicaid along with private insurance companies to help people with hearing loss obtain hearing aids, cochlear implants, assistive listening devices, etc. Is there anything comparable internationally?

In different countries around the world, there are varying levels of funding for hearing aids and cochlear implants, from full or partial state-sponsored funding—mainly through medical plans—to no funding, except for select audiences such as children or persons on social assistance, with some possibility of tax relief for other citizens.

You attended your fourth HLAA Convention in Washington, D.C. What did you come away with?

I always come away with a renewed passion for the work of building a more hearing accessible and inclusive society. The commitment of so many people in this common cause is inspiring and heartwarming.

Now that HLAA and the IFHOH have held a joint Convention/Congress, will the collaboration of the two organizations continue?

Yes! HLAA is a leading voice on hearing loss in the United States and the world, and has a history of leadership in the IFHOH. Rocky Stone, founder of HLAA, was the fifth president of the IFHOH, and Marcia Dugan, former president of the HLAA Board of Trustees, was the seventh president of the IFHOH.

Being the president of such a far-reaching organization as the IFHOH must leave little time for hobbies and pastimes. What do you make time for?

I love fitness, gardening, reading and keeping connected to family and friends. **HLM**



Barbara Liss Chertok lost her hearing suddenly in 1957 at the age of 21 from what was diagnosed 35 years later as Cogan’s syndrome, an autoimmune disorder. She hears with bilateral cochlear implants. Barbara has been a member of HLAA since 1979 and is an active member of the Sarasota/Manatee Florida Chapter.

Barbara has been writing interview articles for Hearing Loss Magazine since 1985. She serves on the National Honorary Board of the American Hearing Research Foundation. Barbara can be reached at barbchert@gmail.com.