

A Hunger for Worldwide Cochlear Implant Advocacy

BY LISE HAMLIN

Recently, CIICA, Cochlear Implant International Community of Action, in their inaugural webinar, “CIICA LIVE,” gave participants a taste of global advocacy. Drawing 90 people from 30 countries, including Australian supporters who had to wake up at 4 a.m. to join, this meeting was a rousing success. This impressive showing right out of the starting gate signals a hunger for support for cochlear implant advocacy work worldwide.

Why all this interest? There may be several reasons. There is a massive gap between the cochlear implant haves and have-nots. Globally, only 1 in 20 who could benefit from an implant receives one. This gap in provision results in a personal and public health issue in dealing with the consequences of unaddressed hearing loss despite the proven benefits of CIs.

Even for people who have already been implanted, there is a strikingly wide variability between countries in provision of equipment, services and/or support. From rehabilitation services for adults to access to free, low-cost or even solar batteries, people in different countries have found creative ways to address local problems. Sharing that creativity represents a huge step toward achieving the goal

Advocacy entails frustration and setbacks as often as solutions and success. We look forward to a lively forum to help lessen frustration, and if we're really lucky, help increase our successes.



Speakers joined the webinar from around the world: From left to right, Top Row: Sue Archbold, coordinator of CIICA of the U.K.; Qais Khan, U.K.; Leo De Raeve, Ph.D., acting chair of CIICA, Belgium. Middle row: Catherine Birman, clinical medical director, Sydney CI Centre; Professor Brian Lamb, CIICA's public policy adviser from the U.K.; and Beatrice Cusmai, vice president of AGUAV, Italy and secretary of EURO-CIU. Bottom row: Paige Stringer, founder and executive director of the Global Foundation for Children with Hearing Loss from the U.S., and Eddie Mukaaya, founder and executive director of Hear His Voice Uganda.

of greater access to implantation and lifelong support for recipients.

CIICA LIVE's agenda included an overview of the *World Report on Hearing CI Advocacy* and *The World Report on Hearing*: summaries—CIICA (ciicanet.org), picking up on key points of the report, including, by the way, that the cochlear implant is “one of the most successful of all neural prostheses developed to date,” (*World Report on Hearing*, 2021, p. 100). Speakers from the U.S., U.K., Italy, Uganda and Australia joined to talk about the *World Report on Hearing* and their perspectives on CI advocacy from the vantage point of their experiences in their own countries.

These ideas presented resonated with the audience, with more than 100 contributions to the chat box and a response to a poll during the webinar, participants expressed eagerness to follow up with other webinars, such

as, “Advocacy: How Do We Do It? and Funding Issues” and “Rehabilitation and Ongoing Support for Adults.”

CIICA's goals include developing a global community of CI advocacy groups, with opportunities to share activities and resources and collaborate to strengthen the user and family voice; providing CI advocates with the tools for change they need to increase access to CI services; and increasing access to the provision of CI and lifelong services globally.

Lofty goals, which, if the webinar is any indication, people around the globe would like to see reached. The webinar's participants were clearly inspired by the exchange of ideas and excited to have a worldwide forum where the consumers' voice can be heard. Finally. **HL**

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HLAA Launches Online Advocacy Group

HLAA is delighted to offer five special interest online subgroups you can join through hlaagroups.hearingloss.org.

Join: <https://hlaagroups.hearingloss.org/g/HLAAAdvocacy>

The HLAA Advocacy subgroup is for people interested in advocating for communication access. This Group has been established to support you: advocates across the country working to make life better for people with hearing loss. We welcome discussion about advocacy locally and federally, tips on overcoming barriers to achieving your goals and those all-important success stories. Our goal with this group is to have a place to exchange information, to support each other and to have a dialogue about the issues that impact us most as well as discuss some of the most effective ways to get there.

Learn more about HLAA Groups at: hlaagroups.hearingloss.org