

CIICA UPDATE: 13 July 2022

OUR NEXT CIICA LIVE AND CIICA CONVERSATION

Please Share!

CIICA has two types of Events

CIICA LIVE: 90 minute sessions with presentations from across the globe on a suggested topic. Learning what is going on elsewhere is inspiring; captioned presentations are available on the website after the event.

CIICA CONVERSATIONS: one hour sessions to discuss in a small group a specific issue which has emerged. These are NOT recorded but a summary of the issues discussed is put on the website.

See below the next two events and join us!

**NEXT CIICA CONVERSATION:
EXPERIENCES OF TINNITUS AND CI
14 SEPTEMBER**

Wednesday September 14th 2022, 19:00UK; 20:00 CET;1400 EST; 11:00 PST; Thursday 15 Sep 04:00 AEDT; 06:00 NZ

Although most forms of ear and hearing problems can be effectively managed with modern technology, tinnitus remains an invisible unaddressed burden to many.

In this CIICA conversation, led by Robert Mandara (Vice-President, EURO-CIU), we would like to hear and discuss your thoughts and experiences on all aspects of tinnitus in relation to CI.

If you are, for example, a tinnitus sufferer, CI user, a parent of a CI user, or a professional working in the CI and/or tinnitus field do join us and have your say! Places are strictly limited, with no space for spectators in this short, one hour discussion! Live captioning will be provided in English and other languages by request.

Register here:
<https://us02web.zoom.us/meeting/register/tZIkceirpjuH9TbgO4ri942rJJleVaMnTlk>

CIICA CONVERSATION: EXPERIENCES OF TINNITUS AND CI



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Robert Mandara



In this CIICA conversation, led by Robert Mandara (Vice-President, EURO-CIU), we would like to hear and discuss your thoughts and experiences on all aspects of tinnitus in relation to CI. For example:

Please register and join this conversation if you are, for example, a tinnitus sufferer, CI user, a parent of a CI user, or a professional working in the CI and/or tinnitus field.

- Do cochlear implants improve or worsen tinnitus? What concrete or anecdotal evidence is there? What are your experiences?
- What do CI users find helps or worsens their tinnitus?
- Are clinics asking about and taking tinnitus seriously?

Places are strictly limited, with no space for spectators! Our CIICA Conversations have small groups and last one hour. Live captioning will be provided in English and other languages by request.

Register here below and have your say!
www.ciicanet.org/events

NEXT CIICA LIVE: YOUNG PEOPLE WITH CI 28 SEPTEMBER

CIICA LIVE: Young people with CI, our opportunities and challenges

**Wednesday 28 September, 20:00 UK; 21:00 CET; 15:00 EST; 12:00 PST;
Thursday 29 September, 05:00 AEDT; 07:00 NZ**

Chaired by Bowen Tang, CI User, and President of the International Federation of Hard of Hearing Young People, IFHOHYP, young CI users, families and those providing services for young people around the globe will contribute to this 90 minute session.

Young CI users and their families, and providers of services will share their experiences about the challenges and opportunities at home, school, higher education and work.

We can all learn from what the young people tell us: as Bowen recently commented: *“ We don’t know what we don’t know... our technology has to last us a lifetime... we need to take ownership of it”*



What can we learn and provide for their future services to ensure lifelong provision and maximise the benefits of CI for this new group of young people?

Register here:
<https://us02web.zoom.us/meeting/register/tZMtcuiprTMqEtMb8APM9oqMKJQFGYlrBdDn>

After registering, you will receive a confirmation email containing information about joining the meeting. Full programme and speakers available soon!

CIICA CONVERSATION ON LIVING GUIDELINES PROJECT.. WHAT DID WE SAY?

The Living Guidelines initiative is an important project to improve global access to CI and CI services and to promote best practice. Our CIICA Conversation with leaders from our global network provided an opportunity for 23 adult CI users, family members and professionals from 14 countries to comment on the project and how we can help with the development and dissemination of the guidelines to ensure they are effective.

There was a consensus of opinion that the Guidelines offer an exciting opportunity to address the **lack of awareness of CI** not only in society but with professionals, including audiologists. There was also consensus that **practices for CI for adults are hugely varied, and having agreed guidelines would provide opportunities to increase access to CI and to rehabilitation services.**

The participants were keen to ensure that CI is set in the context of person-centred care and that users are involved in the development and management of hearing technology. The value of peer-to-peer support was seen as key:

"Peer support offers safe space and place where you can ask any question you would never ask hearing care professionals"

The challenges of managing the technology in daily life led to stimulating discussion in the chat room:

"Some of the assistive technology is so hard to use that I'm still struggling with it as a user after 8 years!"

See the fascinating summary of the conversation at <https://ciicanet.org/events/ciica-conversation-adults-with-ci-talking-about-the-living-guidelines/> and more information on the project at <https://ciicanet.org/2022/03/02/living-guidelines-project/>

"This is really exciting: I look forward to seeing how this develops."



THE TECHNOLOGY IS JUST THE BEGINNING

PAIGE STRINGER, OF THE GLOBAL FOUNDATION FOR CHILDREN WITH HEARING LOSS TELLS US WHY

One of our Founder Members, The Global Foundation For Children With Hearing Loss (www.childrenwithhearingloss.org), works with deaf children and their families in low resource countries, working with government and other local partners across hearing health care and early education. They work currently in Mongolia, Nepal and Vietnam to establish early identification, hearing technology, professional expertise, and family support for these children in the long term. Paige Stringer, herself a CI user, leads the work and writes in The Hearing Journal why The Technology is Just the Beginning: go to <https://ciicanet.org/community/community-news/>

And do send us your news, resources and research to share on our active website

FIRST RESULTS OF THE ADULT SURVEY 1283 RESPONSES... THANK YOU!

Thanks to all the 1238 who responded to our Adult CI survey where we asked what services are currently provided and what people would like. Full analysis underway but the first summary is available to download at <https://ciicanet.org/2022/06/22/sharing-initial-data-from-our-survey-of-adults-with-ci-thanks-to-you-all/>

- 1238 respondents agreed to participate in the survey, Representing 40 countries
- Highest numbers of respondents from Germany, Australia, Brazil, United States, United Kingdom, France and New Zealand but good global coverage
- Ranged in age from 18 to 91 years; 10% under 30 years of age; Largest percentage (47%) between the ages of 55 and 75
- Most (94%) reported a bilateral hearing loss ; Only (37%) used two implants ; Of 771 using one CI, 55% use a hearing aid in the other ear

These first figures are only the beginning of the story - your thoughtful contributions to the survey will provide great insights and enable us to produce a powerful report. We have much more to do!

IFHOH WORLD CONGRESS, BUDAPEST 22-24 SEPTEMBER 2022

IFHOH's 2022 World Congress, **WORLD WITHOUT BARRIERS** is in the beautiful city of Budapest from 22-24 September. It will be held in the Ensana Thermal Hotel on Margaret Island. Ruth Warick, President, will welcome you to this face-to-face meeting, providing great opportunities to meet up again with your colleagues and friends.

To see more details of the exciting programme and for link to register see <https://ciicanet.org/community/member-events/> or go to <http://www.ifhoh2022budapest.com>



UKRAINE: HUMANITARIAN SUPPORT FOR THOSE WITH HEARING LOSS ARRIVES! MORE HELP NEEDED

So many groups are helping to get the resources needed to Ukraine - see below the photos sent by Maks to show the resources have arrived! With

the devastating and fast changing situation it is hard to know what words can describe it. But such a lot is happening to support by humanitarian groups for those with hearing loss. Have a look at what is happening and see how you can help - and see the video prepared for International CI day for EURO-CIU by the Ukrainian group.

Go to [News – CIICA \(ciicanet.org\)](https://www.ciicanet.org/news)

Communication for those with hearing loss is even more important in a crisis.



THE IMPACT OF THE PANDEMIC: MEMBERS' VIDEOS AVAILABLE

Our members have made excellent short videos of the impact of the pandemic - If you missed them - have a look to see what you have missed! These videos are really helpful resources for advocacy work. Go to [THE IMPACT OF THE PANDEMIC: WHAT HAVE WE LEARNT? MEMBERS' VOICES – CIICA \(ciicanet.org\)](https://www.ciicanet.org/news) They are really useful resources for your advocacy work.

**Welcome to new members who have
joined us recently! Send us your news,
events and resources**

info@ciicanet.org

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