

CIICA.AISBL Annual Report 2023

CIICA became a legal entity as an International Non-Profit Association, AISBL, based in Belgium, on 8 February 2023: The financial year is now Jan – 31 December.

CIICA was formed as a global network in 2021, following an international consultation of stakeholders who asked for an active, light touch network with minimal bureaucracy. See Foundation Document: [Why CIICA? – CIICA \(ciicanet.org\)](https://www.ciicanet.org/why-ciica/).

CIICA's agreed goals are:

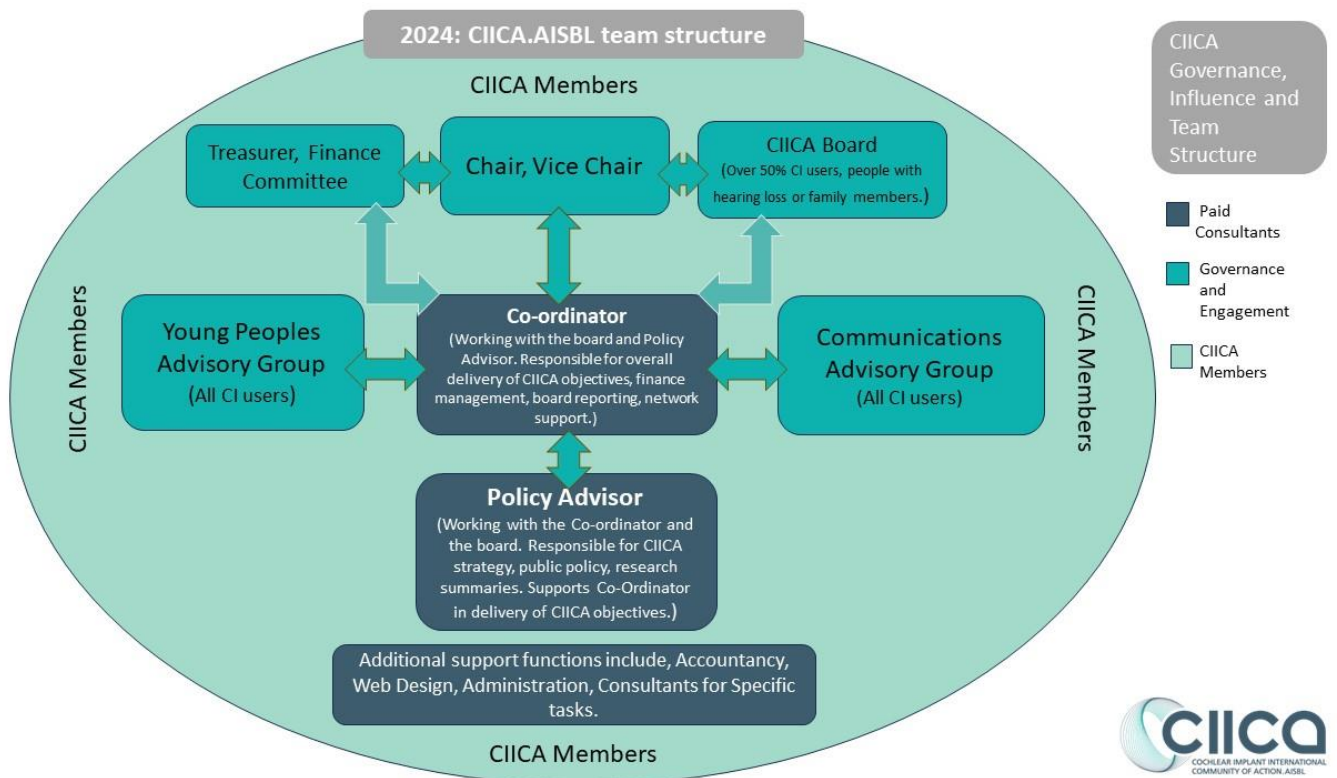
- 1. To develop a global community of cochlear implant (CI) advocacy groups and individuals, with opportunities to share activities and resources and collaborate to strengthen the user and family voice.**
- 2. To provide CI advocated with the tools for change they need to increase access to CI services.**
- 3. To increase access to the provision of CI and lifelong services globally.**

During 2023 CIICA became a legal entity, establishing its own bank account, and agreed the following statement describing CIICA's way of working:

- As a voluntary network organisation, the resources we have should be prioritized towards ensuring the greatest possible impact and support for the network rather than supporting organisational structures beyond what is absolutely necessary to achieve and sustain operational efficiency*
- As a voluntary association, we pledge to maintain a simple organizational structure that achieves the first aim above and minimises risk, rather than more hierarchical ways of working.*

In order to share responsibilities, reduce bureaucracy, act nimbly, and be responsive to our constituents, CIICA's consultants were retained to carry on essential work and support the work of volunteers with specific areas of interest and expertise. As a result of the year of growth, CIICA has amended its team structure from our original one, incorporating these developments, while reflecting our way of working. See the following figure:

CIICA TEAM 2024:



CIICA's 2023 Business Plan focussed on:

- **Governance**
- **Sustainability: Funding and Partnerships**
- **Development and Support of the Network**
- **Developing Policy and Evidence**

Overview of our achievements in these areas during 2023:

Governance:

- CIICA became **CIICA.AISBL BE0798.221.710** in February 2023, as a legal entity based in Brussels, Belgium, with a Board of 9 Members and 3 Full Members. CIICA.AISBL has a Chair, Leo de Raeve, a Vice-Chair, Harald Seidler, a Treasurer Ruth Warick, and a Coordinator, Sue Archbold, all named in the Statutes.
- CIICA.AISBL opened its own bank account with KBC Bank International in Belgium; previously, the International Federation of the Hard of Hearing (IFHOH) had provided financial management which was essential in the initial phases of CIICA. Financial guidelines agreed by the Finance Committee and the Board were revised and updated as a result of the changes.
- CIICA's legal address change to Maison des Associations Internationales (MAI), 40 Rue Washington, Brussels, 1050 in Brussels is underway, overseen by our accountant. MAI also provides facilities in Brussels.

- Jean-Pierre Gilissen was appointed Accountant; he is responsible to prepare our accounts as required under Belgian law. He is also licensed to be able to make changes to our statutes when required.
- CIICA joined the Federation Associations Internationale in Belgium (FAIB) which provides updates on Belgian law.

Sustainability: Funding and Partnerships

Sustainability was a major concern and focus during the year, as for other non-government organisations (NGOs). CIICA took steps to address this issue in 2023, including the major one of becoming a legal entity. In addition:

- Sources of funding increased during 2023: two research grants, earned income from activity, donations, two Industry sources
- An administrative assistant was hired as a part time contractor to support the coordinator with data gathering, process creation and management, website administration and day-to-day operational support.
- An accountant was contracted to take on quarterly reporting to the Board and end of financial year (31 December) audit.
- The developing Young Adults Global Advisory Group made strides, led by Qais Khan, a Board Member, with other volunteers, facilitated by Sue Archbold and Robert Mandara
- A new Board member, Paige Stringer, has been accepted to be appointed in 2024
- Key global opinion leaders took on voluntary leading roles for example leading specific focussed Conversations, and CIICA LIVE events and preparing resources and journal and magazine papers.
- CIICA.AISBL became a member of the WHO World Hearing Forum: Note: Ruth Warick and Sue Archbold are members of the World Hearing Forum Steering Committee
- Organisations and individuals of the network are taking on increasing roles in the activities of CIICA.AISBL (see below for additional details and statistics)

Development and Support of Network: (detailed figures below)

- Steady increase of the membership, particularly individuals and CI users
- Increase in reach geographically and in interests of members
- Increase in number of CIICA Conversations
- Increase in website unique visitors and activity
- Increase in uptake of CIICA UPDATES and use of social media
- Production of advocacy tools for the network
- Increased international conference and workshop attendance by CIICA TEAM

Developing Policy and Evidence:

- Production of research evidence: publication of reports and peer-reviewed journal papers
- Young People's research and preparation of report and Declaration
- Policy Briefings including *Living Guidelines*, *CI Services Matter*

More Specifically, our achievements during 2023:

Finance

In spite of the significant costs of establishing CIICA.AISBL and the increased amount of administration costs resulting from this move, CIICA expenditures remain on track, and as anticipated, with an increase in the range of income streams: two industry sponsors, two research grants, earned income and donations. Systems are in place for regular monitoring by the finance group, reporting to the Board. The appointment of our new accountant in September 2023 will take on some of the everyday financial duties which have been carried out by Leo De Raeve, Sue Archbold and Ruth Warick and will also ensure that we are in line with Belgian law, where there have been significant changes. The accountant is also familiar with our bank, KBC, and their requirements. He will monitor and report quarterly and prepare the end of year accounts.

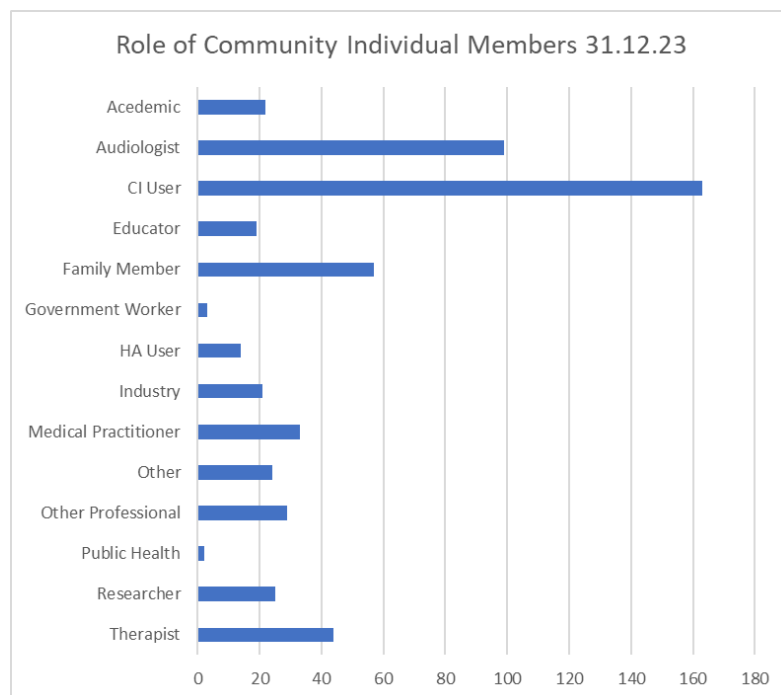
In preparation for 2024, the budget has been agreed and set conservatively by the Finance Group and Board, bearing in mind global uncertainties.

Members of CIICA

As at end of December we have 556 individuals, (an increase of 20% over 2022) from 66 countries (59 countries at the end of 2022): there is steady growth of individual members. New countries represented include Uzbekistan, Ukraine, Armenia, Palestine, Libya and Jordan.

Top countries for membership are respectively USA, UK, Australia, Netherlands, Germany, Canada, Belgium, France, Brazil. Continued growth is noted in South America and the top countries change according to where activity has taken place.

The figure below illustrates the reported major roles of our members (although some have more than one role): and CI users are the most common group, in line with our goal.



Global organisations:

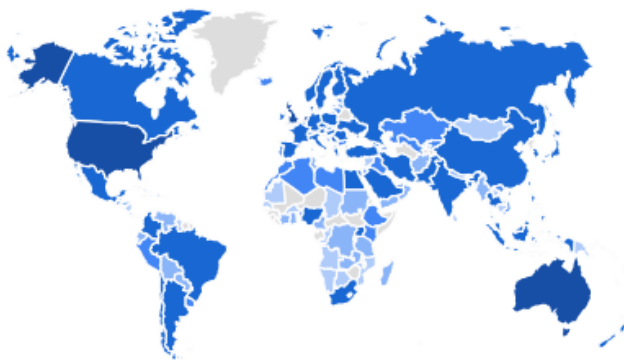
We now have 109 organisations in our network from 38 countries: see the list on website at www.ciicanet.org/community with representation, including individuals, in 66 countries in total.

Website activity

The CIICA website is primarily for the network members and not an outward facing website. Thus, it is not expected to have high traffic figures, but rather that network members share the information themselves, which is difficult to quantify. The sharing of news, resources and events is particularly active and important to users. The image below reflects the use of the website for the period January 1 to December 31, 2023 and increased use in the United States, Australia, Germany, The Netherlands, Belgium, Canada, across Africa and S America. The decrease in percentage of the UK likely reflects the increasing global activity of CIICA, as opposed to less activity in the UK.

Top languages used: English, Dutch, German, Spanish, Portuguese, Franch, Italian.

Users by Country ID



COUNTRY		USERS
United States	1.6K	↑18.9%
United Kingdom	1.1K	↓22.5%
Australia	610	↑5.2%
Netherlands	479	↑4.8%
Germany	323	↑36.3%
Canada	281	↑9.3%
Belgium	258	↑32.3%

1 Jan - 31 Dec 2023

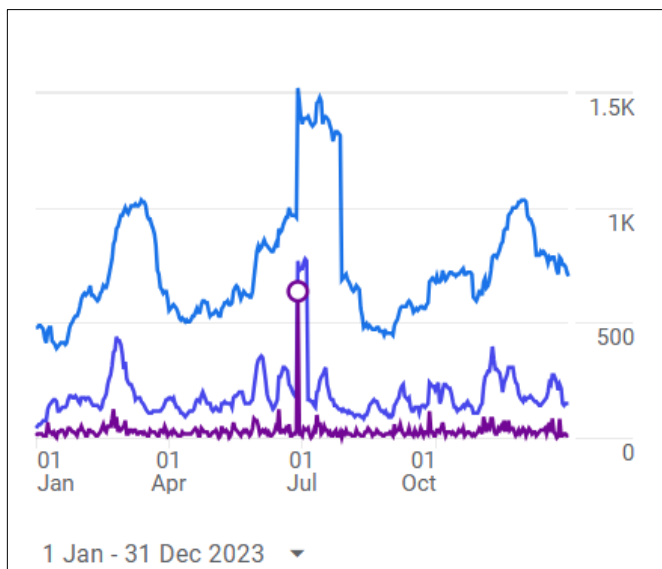
[View countries](#)

Activity Summary: 2023 compared to 2022

The following table illustrates the year's activity against the preceding year, and summarises activity, showing steady increase in users, events and views.

Activity	Total for 2023	Total for 2022
User engagement	21k	19.9K
Users	8.3k	7.2K
Events	99.6k	83.7K
First visit	8.4k	7.1K
File downloads	2.2k	2.2K
Page views	36k	28K

The following graph shows user events for 2023 for 30 days, 7 days and 1 day. The peak in March is our birthday, CI International day and World Hearing Day but there is a steady encouraging upward trend over the year. There is an interesting peak in July and in November, both occasions where there were big international conferences and CIICA had a presence.



The figure shows user activity for 2023 showing activity for 30 days, 7 days and 1 day.

After each CIICA UPDATE there is increased activity on the website and the events, news and resources pages are well used; research roundups are also popular, giving the busy network the information in an accessible format.

It was encouraging to see the Community Members area of the website increasingly used to share news, events, resources. Resources from CIICA and members are increasingly downloaded. We are also aware that many national and local networks then share the resources onwards within their own networks. We have no direct way of measuring this at the moment but informal feedback suggests this leverages the impact of the resources many times over.

COMMUNICATION AND ONLINE ACTIVITIES

CIICA now has two main online events which are now well established, and provided with live captioning in English as well as other languages upon request:

CIICA LIVE Events have presentations on specific requested topics important to users and families every 2 months; these promote discussion through the chat room. The majority of presentations are delivered by CI users and families and the captioned presentations are available afterwards at [Events – CIICA \(ciicanet.org\)](https://www.ciicanet.org/events). These events typically attract about 100 registrations from about 30 countries.

Topics in 2023:

- Delivering person and family centred CI Services
- The Living Guidelines: The impact on Adult CI Services and Access
- CI Services Matter: Launch of the Global Survey Report

CIICA CONVERSATIONS: small groups (max 20) having a facilitated discussion on a specific suggested topic for one hour. There are no presentations, but a summary of key issues which emerge during the conversation is shared on the website and in members' social media and own sites. During 2023 these have become increasingly popular, with some topics developing their theme and the issues, and with expert volunteers leading them, and writing them up. The Conversations are becoming ongoing topics, bringing together global interested groups, which are leading to activity.

The Conversations on the Living Guidelines project over 2022 and 2023 led to our production of a summary and influenced the final report and influenced the recommendations. Summaries of the eleven Conversations are available at: [Events – CIICA \(ciicanet.org\)](https://www.ciicanet.org/events)

Topics for our Conversations in 2023:

- Person Centred Care in CI Services
 - Person Centered Care in CI Services
 - Moving on with Person Centered Care
- Young Adults with CI:
 - What are your communication challenges and how do you manage them?
 - What changes are needed?
 - Transition to the workplace
 - Travels with my CI
 - How's your social life?
- Tinnitus :
 - Trajectories with CI
 - One person's hiss is another person's sizzle
- Consulting on the Living Guidelines
- Why Parents' Groups?

CIICA Conversations have become an important resource for developing and refining policy positions of participant organisations and establishing what issues are most important to the network. The summaries of these sessions are also valued as tools for developing further thinking and recording the views of the sector.

Of particular interest in 2023 has been the development of the Conversations for Young Adults with CI, led by Board member Qais Khan, facilitated by Sue Archbold, and Robert Mandara, member of the

Communication Group. Two conversations were held in 2022 and five in 2023; these have led to the formation of a global Advisory Group to work on a Report and Declaration to be launched in 2024.

RESOURCES

In addition to sharing the resources of members, CIICA has produced useful resources available from www.ciicanet.org/resources:

Living Guidelines Project Resources

- The goal of the Living Guidelines Project was to increase access to CI and to provide recommendations for evidence based practice for adult CI services. CIICA’s Chair, Leo De Raeve, was one of the co-chairs for this project and CIICA was pleased to contribute the users’ perspective into the process. This collaboration began in 2022, with CIICA providing the opportunity for the network to be involved in the development of the guidelines via four CIICA CONVERSATIONS. During 2023, this resulted in the production of a summary of the Conversations as an advocacy resource. The voices of CI users captured by the Conversations influenced the report and its recommendations to include functional and quality of life outcome measures, and reference to psychological services and peer group support.
- For the launch of the Living Guidelines in July 2023, a CIICA Summary of the Recommendations was developed as an advocacy tool together with a video produced with PINDROP, NZ, to demonstrate what users could expect from the guidance. Summary of the Living Guidelines: [CIICA’s summary of The Living Guidelines for Adult CI – CIICA \(ciicanet.org\)](#)

CI Services Matter: Briefing from the global adult survey

- A Briefing from the global adult survey, CI SERVICES MATTER was developed as an advocacy tool following the full report: [CIICA-CI-SERVICES-MATTER-BRIEFING WEB-FINAL-2.pdf \(ciicanet.org\)](#)

Other resources

All resources from CIICA are available from Resources available from CIICA.AISBL to support your CI advocacy work – CIICA (ciicanet.org) and the resources page of the website shares resources of members to be available to the entire network.

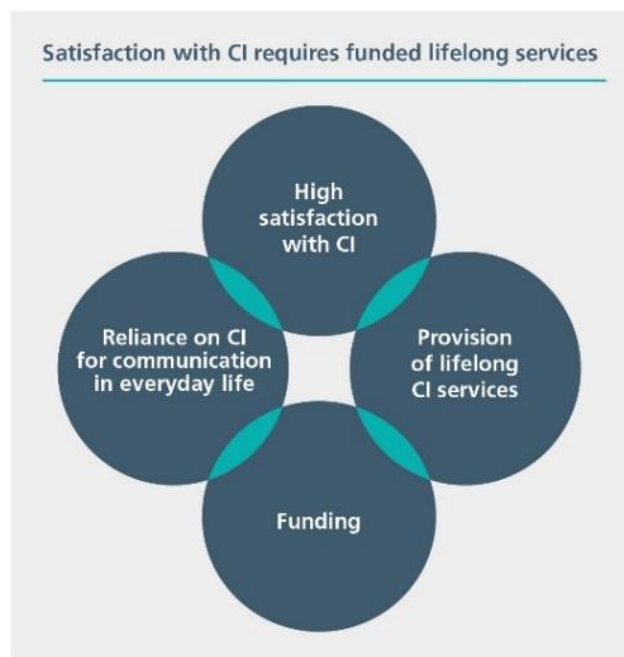
RESEARCH

Cochlear Implants in Deaf and Deafened adults: a global consultation on lifelong aftercare

With a research grant from Social Sciences and Humanities Research Council, Canada, via York University, Toronto, with the Principal Investigator, Professor Connie Mayer, this research was completed and reported in 2023. The research had over 1,000 responses from 40 countries and the completed report, CI SERVICES MATTER, was launched at the EUROCIU meeting in Spain, November 2023, with its Briefing.

The key issues were:

- High levels of satisfaction with CI and hence reliance on CI for everyday communication
- Little rehabilitation for adults, and a lack of spares, repairs and replacements
- The need for lifelong funded CI services



The work received wide publicity and support including pieces in ENT and AUDIOLOGY NEWS, the Hearing Journal and the Canadian Audiology Journal. Further reporting from the data collected is underway looking at the issues for young adults with CI, who were implanted as children.

A grant has been received from AICE, the Spanish group, to carry out further research with the young adults with CI and a further report, Young Adults with CI Matter, will be launched on CI International Day 2024, using the specific data from the survey, and will include the analysis of the seven Conversations, and work by the Advisory Young Adults group.

COMMUNICATIONS

Social Media

The Twitter feed grew during 2023 with regular activity; 47 posts during the year and currently 315 followers, and with the establishment of LinkedIn page.

CIICA Updates

CIICA updates are sent to members every two weeks: information about online events, resources, members' news and activities, research news. These are shared through the network, and result in increase in website activity. Over 50% are opened within three days by both individuals and organisations. Take up by our network has increased over the year; for example, the last CIICA UPDATE of the year in the usually quiet time of December had the largest percentage of downloads ever for CIICA.

Conference and workshop participation:

CIICA attended several conferences this year with invited presentations, accepted papers, invited participation in Round Tables, and our first exhibition stands, resulting in more members and activity. These include:

- Leo De Raeve at IFOS, Dubai, on the Living Guidelines.
- Qais Khan at UN, New York, at Young People 2030, on sustainable cities. Thanks to International Federation of Hard of Hearing Young People.
- Qais Khan, Brian Lamb and Sue Archbold at the Global Summit for Young People with the Malala Foundation and Cochlear Foundation.
- Brian Lamb at British Cochlear Implant Group, Cambridge on the adult survey.
- Leo De Raeve, Qais Khan, Brian Lamb, Sue Archbold at ESPCI, Rotterdam on sustainable CI services, young adults and economics, with a free stand to showcase our resources.
- Sue Archbold, Paige Stringer and Eddie Mukaaya on line presentations at the 7th Emerging Nations Conference, Istanbul.
- Helen Cullington as APSCI conference, Hong Kong: CIICA Conversations.
- Teresa Amat, Sue Archbold, Leo De Raeve at EURO-CIU, Valencia: launch of CI SERVICES MATTER and update on CIICA activities .
- Ruth Warick, Teresa Amat, Leo De Raeve, Brian Lamb, Sue Archbold, Paige Stringer: World Hearing Forum, WHO: participation in Steering Committee and workstreams.
- Sue Archbold: ONLINE: Cochlear Science and Research Seminar: Healthy Ageing
- Sue Archbold and user and family volunteers: Online workshops for Sensorion teams.
- Leo De Raeve, Cochlear workshops, Poland.

Journals and articles:

- EURO-CIU Newsletter: four articles
- *International Journal of Audiology: Cochlear Implants and Deafness*: a global case study to increase policy awareness and action on an under-resourced health issue. Brian Lamb, Sue Archbold, Zheng Ng [Cochlear implants and deafness: a global case study to increase policy awareness and action on an under-resourced health issue: International Journal of Audiology: Vol 0, No 0 \(tandfonline.com\)](#)
- *Hearing Journal*: Kris English, CI changes lives [Cochlear Implants Can Change Lives! A New Global Network is... : The Hearing Journal \(lww.com\)](#)
- *ENT and Audiology News*: CI Services Matter
- *Canadian Audiology Journal*: CI SERVICES MATTER
- Leo De Raeve: Ramos-Macías A., De Raeve L., Holcomb M., Connor E., Taylor A., Deltetto I. and Taylor C., *Strategies for the implementation of the living guidelines for cochlear implantation in adults*, *Frontiers in public health*, open access, 15 December 2023, DOI 10.3389/fpubh.2023.1272437

CIICA's increasing global impact

During this year there have been many examples of the impact of the work of CIICA in supporting the global network in addition to the direct contacts through CIICA CONVERSATIONS. These include:

- Our Children's Briefing has been used widely to influence the provision of children's services, including in Australia by network members where there are concerns about the quality of CI programming services.
- Again from Australia an email following our Report CI SERVICES MATTER: *Thanks so much this is just what I need to make the business case for adult rehabilitation*
- CIICA's impact to support policy and provision change, for example from Kenya: *We've finally received some audiology equipment and are on our way to setting up a Hearing Center to provide early childhood hearing screening and interventions. We are hoping to establish the first public/community audiology program to reach a wide section of the underserved populations with training, awareness on ear/hearing care! Thanks for all the lessons we're drawing out of our association with the CIICA family.*
- Influencing the Living Guidelines Recommendations ensuring that CI Users had a voice and that their issues and priorities were included in the final recommendations
- Participation and influence at the World Hearing Forum, as part of the Steering Committee
- Increased invitations to participate in conferences about the activities of the network
- The increased reach and website activity.

Looking to the future

CIICA's Board and consultants are working on the priorities for its Business Plan for 2024 onwards to sustain CIICA.AISBL as a network for promoting access to CI and to advocating for lifelong CI services for all who need them. There is increased evidence for advocacy activities and increased examples of the effectiveness of many of the networks within CIICA.

The First Global Conference on CI Advocacy in Action will be held at MAI, Brussels, on 9/10 May 2024 and already is receiving great interest. It will be opened by Dr. Shelly Chadha, Technical Lead, World Health Organization. This will enable the CIICA Network to be a reality rather than entirely virtual, and CIICA.AISBL will hold its first General Assembly there on 9 May 2024.

With thanks to all for their support and enthusiasm and we look forward to 2024.

Leo De Raeve, Brian Lamb and Sue Archbold, on behalf of the CIICA team
As at 31st December 2023.

CIICA TEAM:

International Steering Group:

Teresa Amat, Parent, Speech Therapist, President European Association of CI Users (EURO-CIU)

Leo De Raeve, PhD, Director, ONICI, Scientific Advisor to EURO-CIU, Belgium

Qais Khan, CI user and advocate, UK

Eddie Mukaaya, Parent, Founder and Executive Director Hear His Voice, Uganda

Barbara Kelley, Executive Director of the Hearing Loss Association of America (HLAA), USA

Darja Pajk, CI User, Occupational Therapist, Board Member of European Federation of Hard of Hearing

Lee Schouskoff, Chief Executive NCIT, PINDROP Foundation, New Zealand

Harald Seidler, MD, CI User and ENT specialist, DSB, Germany

Ruth Warick, HA user, Immediate Past President, International Federation of Hard of Hearing (IFHOH),

WHO World Hearing Forum Steering Committee Member, Canada

Invited Member of the Board: Paige Stringer, CI and HA User, Founder and Executive Director of the Global Foundation For Children With Hearing Loss, USA

Communication Group:

Anita Grover, CI user, Chief Executive AVUK

Lise Hamlin, CI user, Director of Public Policy, HLAA, USA

Qais Khan, CI user and advocate, UK

Robert Mandara, CI user, Vice President EURO-CIU, Finland

Co-ordinator: Sue Archbold, PhD

Public Policy Advisor: Brian Lamb, OBE

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