

CIICA.AISBL Annual Report 2024

The Cochlear Implant International Community of Action is a global network which aims to close the gap in Cochlear Implant provision and ensure lifelong support for all who could benefit.

Our 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 advocates 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.

CIICA's 2024 Business Plan focussed on the following areas and this reports reviews 2024 under the same headings:

1. Governance
2. Finance and Sustainability
3. Development and Support of the Network
4. Developing Policy and Evidence

1. GOVERNANCE

CIICA's agreed 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.*

During 2024:

- CIICA's legal home became Maison des Associations Internationales (MAI), 40 Rue Washington, Brussels
- CIICA held its first General Assembly at MAI, on 10 May 2024
- CIICA's financial report for 2023 was accepted and submitted by our accountants to the Belgian authorities
- A new member of the Board, Paige Stringer, was formally accepted at the CIICA General Assembly and papers were subsequently presented to the Belgian authorities
- Seven board meetings were held during the year, with minutes agreed and signed by the Chair.

2. FINANCE AND SUSTAINABILITY

Finance and Sustainability were a major concern and focus during the year, as was the case for other non-government organisations (NGOs). Despite increased administration costs resulting from CIICA becoming a legal entity and the costs of our first international conference, CIICA expenditures remained on track. We had an increase in the range of income streams, these being industry sponsors, research grants, earned income and donations. We had three industry sponsors and two research grants during the year.

Systems are in place for regular monitoring by our Finance Committee which reports to the Board. In addition, our Belgian accountant ensures that we are in line with Belgian law, which changed significantly during the year. The accountant is also familiar with our bank, KBC, and their requirements. He monitors and reports quarterly and prepares and submits the end-of-year accounts. He also takes care of the UBO ('Ultimate Beneficial Owners) registration of all board members, makes quarterly submissions of our accounts into the platform of the Federal Public Financial Service Department and produces and submits our annual accounts.

Other noteworthy points related to finance and development of sustainability of CIICA:

- CIICA performed to its agreed 2024 budget.
- Sources of funding increased during 2024: research grant, earned income from activity, private donations, three Industry sources.
- A further research grant submitted to the Canadian Social Sciences and Humanities Research Council, to explore the global experience of parents and families of CI services.
- Further donations sought from a range of funders.
- Day-to-day operational support provided by administrative assistant as a private contractor.
- Key global opinion leaders are taking on further voluntary roles: for example leading specific focussed Conversations and CIICA LIVE events, preparing resources, and writing journal and magazine papers.
- Organisations and individuals of the network are taking on increasing roles in the activities of CIICA.AISBL

In preparation for 2025, the budget has been agreed and set conservatively by the Finance Committee and Board, based on present activity and the Business Plan for 2025, bearing in mind global uncertainties.

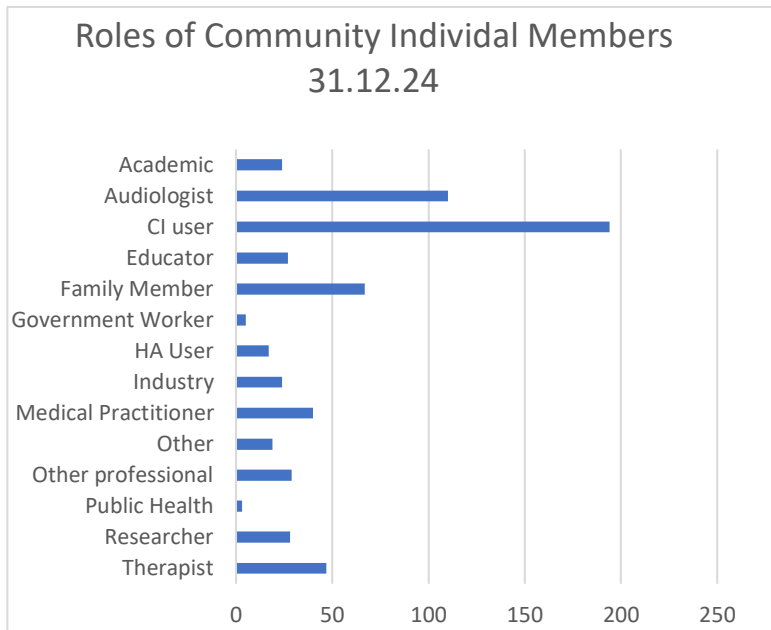
3. DEVELOPMENT AND SUPPORT OF THE NETWORK

Members of CIICA

The network continues to grow steadily. As at end of December we have 639 individuals, (an increase of 23% over 2023) from 74 countries (66 countries at the end of 2023): there is steady growth of the numbers of individual members and they contribute diversity in their wide range of backgrounds.

Top countries for membership are, respectively, United States, United Kingdom, Australia, Netherlands, Germany, Canada, Belgium, France, and Brazil. We are experiencing continued growth in South America and SE Asia.

The figure below illustrates the reported major roles of our members (recognizing that some have more than one role). CI users are the most common group, in line with our goals, but with increasing membership from across a range of backgrounds.



Global organisations:

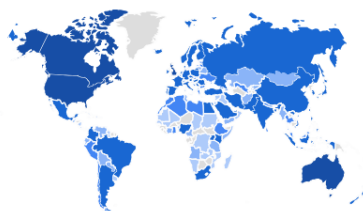
We now have 122 organisations in our network from 42 countries, a growth of 11% from the previous year. See the list on website www.ciicanet.org/community Our global representation, including individuals, is 74 countries.

Website activity

The CIICA website is primarily for the interaction and support of network members and not an outward facing website. Thus, it is not expected to have high traffic figures, but rather be a platform for network members to share the information themselves, which is difficult to quantify. However, we have seen significant growth in all areas of activity in 2024. In summary:

- **32% increase in active members**
- **29% increase in user engagement**
- **51% increase in events**
- **31% increase in first visits**
- **75% increase in page views**
- **64% increase in file downloads**

Active users by Country ID



COUNTRY	ACTIVE USERS	% Change
United States	2.5K	↑54.8%
United Kingdom	2K	↑78.5%
Canada	604	↑114.0%
Australia	562	↓8.5%
Netherlands	463	↓3.5%
India	458	↑136.0%
Belgium	431	↑66.4%

1 Jan - 31 Dec 2024

[View countries](#)

The sharing of news, resources, and events is particularly active and important to users. The increase in page views and file downloads indicate that our members find the site and its resources useful to them.

The image shown on the left reflects the use of the website for the period of January 1 to December 31, 2024 with increased use from those in the United States, UK, Canada, India and Belgium.

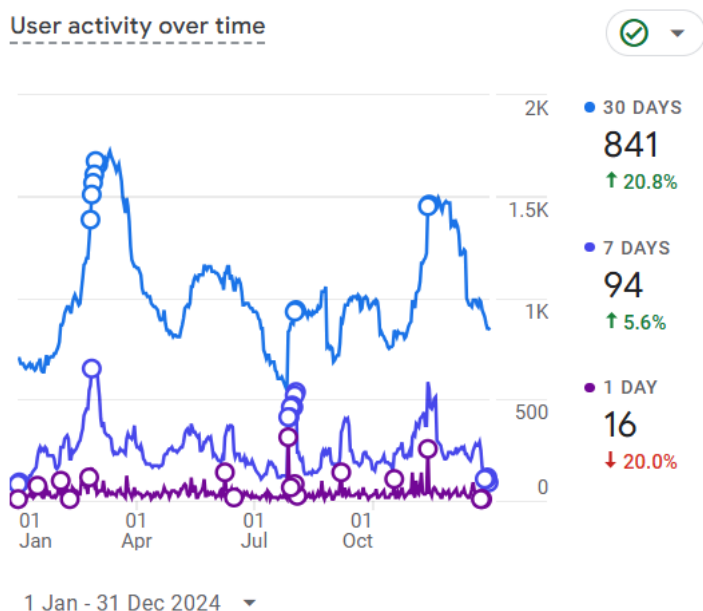
Top languages used: English, Dutch, German, Spanish, Portuguese, French, and Italian, with increasing use of Chinese, Romanian and Swedish.

Website Activity Summary: 2024 compared to 2023 and 2022

The following table illustrates the year’s activity compared to preceding years, and summarises activities, showing a steady increase in users, events and views. It was encouraging to see the Community Members area of the website increasingly used to share news, events, and resources. Resources from CIICA and members are increasingly downloaded. We are also aware that many national and local networks share the resources onwards within their own networks. We have no direct way of measuring this activity at the moment but informal feedback suggests a leveraging of the impact of the resources many times over.

Activity	Total for 2024	Total for 2023	Total for 2022
User engagement	27K	21k	19.9K
Active Users	11K	8.3k	7.2K
Events	151K	99.6k	83.7K
First visit	11K	8.4k	7.1K
File downloads	3.6K	2.2k	2.2K
Page views	63K	36k	28K

The following figure shows user activity for 2024 for periods of 30 days, 7 days and 1 day.



Peaks were in March (March 3 is World Hearing Day) when we launched the young people’s report and in February (Feb. 25th is CI International Day). As well, there is a steady upward trend over the year.

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, during which information is provided in an accessible format to the network.

ONLINE ACTIVITIES

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

CIICA LIVE Events consists of presentations on requested topics important to users and families; these events 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). Each of these events typically attract about 100 registrations from about 30 countries.

Topics in 2024:

- **Advocacy in Action:** following our Conference, with Prof Sara Rubinelli and Prof Carolina Der, of WHO : presentations at [CIICA LIVE: CI ADVOCACY IN ACTION – CIICA](#)
- **CI in Low and Middle Income Countries:** presentations at [CIICA LIVE: CI PROVISION IN LOW RESOURCED COUNTRIES – THE CHALLENGES – CIICA](#)

Both these topics will be developed further in 2025 for small group CIICA Conversations.

CIICA CONVERSATIONS: small groups (max 20) have 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 as well as in members' social media and own sites. During 2024 these have become increasingly popular, with some topics developing their theme and the issues, with expert volunteers leading them, and writing them up. The Conversations are becoming ongoing topics, bringing together global interested groups, which are leading to action.

Themes for our 12 Conversations in 2024:

- Person-Centred Care in Adult CI Services
- Young Adults with CI
- Tinnitus and CI
- Issues for Parents

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. They are currently being written up for publication in peer-reviewed journals.

INTERNATIONAL CONFERENCE: CI ADVOCACY IN ACTION, BRUSSELS, MAY 2024

CIICA held its first in person conference: CI Advocacy in Action. We welcomed 100 delegates from 28 countries across the globe and over half were CI users or family members, in addition to surgeons, audiologists, therapists, teachers, industry and public policy specialists being in attendance. Professor Graeme Clark, a



CI pioneer, opened the conference supporting the goals of CIICA, followed by Dr Shelly Chadha, of WHO, providing inspiration for Ear and Hearing Care, including CI services.



The conference had extremely high ratings:

- Venue 92%
- Presenters 98%
- Content 94%
- Overall 96%

The comments included what they found useful and the impact:

- *I feel inspired and energized*

- *Now to think about how to be part of this community and spread the word in my country with your support.*
- *The different groups talking about their advocacy – truly inspiring*
- *Young people amazing*
- *Taking away the new ideas and inspirations from this event for us*
- *Learning how things work in other countries*

Global networking was clearly key - providing an atmosphere in which people could talk freely to each other. The conference had one session at a time, so that everyone could share the same messages. Everyone attended all sessions and remained to the end, which is unusual in CI conferences.

A Talking Wall gave participants an opportunity to share questions, reflections and thoughts. It was a source of rich data about issues for future CIICA Conversations, covering the areas of Parents and Children, Young Adults, Adults and Advocacy Issues and emphasising the inclusion of CI in Ear and Hearing Care for all across the Lifespan. Many common issues emerged in the different areas; these were the most common:



- *Lifelong services – available globally*
- *Raising awareness and tackling lack of information*
- *Access and Support to include monitoring of quality and provision*
- *Rehabilitation being key:*
 - *Tech is just one part -it's nothing unless people are fully supported to maximise potential.*
 - *Industry needs to invest in rehab*
- *Peer group support*
- *Early and effective family support: great tech but nothing without*
- *Young adults should provide information to parents thinking about CI*

- *Young adults are the models for the youth to come*
- *CI Industry: please invest in these young adult CI users: a working group for young CI users? They are the future*
- *Accessible clinic services – online appointment systems*

There were also many questions which people discussed as they were putting them up; many questions about the experience of CI, and particularly about services:

- *What do you wish you knew before CI?*
- *What should future CI users know?*
- *What is one thing you would change about your audiologist?*
- *What is lacking in CI services?*
- *How do you feel about AI and digital services?*



These ideas are feeding into our ongoing CIICA CONVERSATIONS and research.

Follow up on social media, video and by email has been excellent: young people's reflections video on our home page; the video by AVID Books; video from the Georgian, Ukrainian, and Kyrgyzstan and Armenian parents.

Delegates stated:

The conference in Brussels was genuinely one of the most life changing, life affirming and enriching experiences I've ever had - I learnt so much that I'm going to take forwards with me into my personal and professional life.

The conference was a fantastic platform for me to share insights and learn from others, and I am happy to hear that my presentation was useful. The theme "the lived experience" was really the highlight and I was fascinated by the achievements that were presented by the different speakers.

PDFs of the presentations are available at [CI ADVOCACY IN ACTION: FIRST GLOBAL CONFERENCE MAY 2024 – CIICA \(ciicanet.org\)](#) . Insights from delegates are available at [Insights from Delegates: CI Advocacy in Action in Brussels 2024 – CIICA \(ciicanet.org\)](#). The Conference provided us with great opportunities which we built on during 2024 but also confirmed our key role as a network in bringing people together with shared goals in an atmosphere of trust and mutual respect, while also gaining the support of leaders in the field. This was a time and cost- efficient meeting and provided an opportunity to have the latest technology available for CI users to test: with the provision of Blue Tooth Technology and captioning in five languages ***“this was the most accessible meeting I have ever been to”***.

RESOURCES

All resources from CIICA are available from Resources available from CIICA.AISBL to support CI advocacy work – CIICA (ciicanet.org) and the resources page of the website shares resources of members to be available to the entire network. The number of downloads in the year (3.2K) represents a significant influence on the network’s advocacy activities. They include regular research updates, providing summaries for advocacy work, summaries of the conversations. Two major resources during the year:

A PRACTICAL GUIDE TO CI ADVOCACY was launched at our CI Advocacy in Action Conference, following the requests from members and lack of such a guide.



This resource supports user advocates, professionals and all those campaigning to improve aspects of CI access and provision of services. It is based on a series of case studies of successful campaigns, many undertaken by CIICA members, to help advocates think about what would be relevant to their campaigns.

It also outlines an overall plan for improving CI provision and links to other examples, resources and advice for advocates. With this guide, we encourage unified voices and action to increase access to CI and lifelong services. It provides inspiration, advice and knowledge for planning future campaigns with evidence and resources specific to campaigning on CI provision. [CIICA ADVOCACY GUIDE](#) . Videos to support various aspects of advocacy are being developed and some are already available.

This guide is regularly top of internet searches for CI Advocacy.

Young Adults with CI Matter: Report and Briefing from the global survey and their Conversations

The report arose from research with young adults, and includes a video and summary briefing produced as advocacy tools and resources. [YOUNG-PEOPLE-WITH-CI-MATTER.pdf](#) and [CIICA-CI-SERVICES-MATTER-YOUNG-PEOPLE-Briefing.pdf](#)



Young adults are now working on their global Agenda for Change to launch on CI International Day, 2025, with recommendations for the provision of lifelong services, for improved accessibility in education, the workplace and public spaces, and for public education on the awareness of deafness and cochlear implantation.

"CI has surely modernised the concept of deafness".

"I've always heard through a cochlear - so it's all I know".

4. DEVELOPING POLICY AND EVIDENCE

RESEARCH

Young Adults with CI Matter

The data from the global adult survey, CI SERVICES MATTER, was broken down to provide a report on young people with CI: the first group growing up as both deaf and hearing. A report, video and summary briefing were produced as advocacy tools. [YOUNG-PEOPLE-WITH-CI-MATTER.pdf](#) and [CIICA-CI-SERVICES-MATTER-YOUNG-PEOPLE-Briefing.pdf](#) Video at [CIICA – Cochlear Implant International Community of Action](#).

Person Centred CI services

The summaries of the ongoing adult Conversations on Person Centred CI Services have undergone content analysis and are currently being written up for publication, supported by volunteer leading researchers. This paper will lead to the consideration of how we provide and evaluate person-centred CI services.

Parent views of CI services

Following the adult and young adult surveys and report on the services received, discussion was held with international parent group which led to a further submission to the Social Sciences and Health Care Foundation of Canada for a global survey of parents of children with CI. We await the result. It would also enable further Knowledge Mobilisation to take place using the reports from adults and young adults.

Conference and workshop participation:

Increased international conference and workshop attendance by CIICA TEAM: papers, invited talks and leading sessions on CIICA's network activities and the Living Guidelines project:

- CI 2024, Gran Canaria
- British Cochlear Implant Group, BCIG
- HEAL (Hearing across the lifespan), Italy
- EURO-CIU Conference, Vienna
- Hearing Loss Association of America (HLAA) USA
- International Federation of Otolaryngological Societies, (IFOS): Dubai and Vietnam
- World Congress of Audiology, Paris (Living Guidelines, and Adult and Young People Research, Ethics session)
- CIGICON, India
- 3rd Arab CI conference, Abu Dhabi (Living Guidelines)
- B-audio & B-ENT conference, Brussels
- Workshops for Sensorion



Increasing partnership working with groups including World Hearing Forum, International Federation of Ageing, Bluetooth, European Federation of Hard of Hearing, International Federation of Hard of Hearing, International Federation of Otolaryngological Societies, International Society of Audiology. Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) .

Social Media

The X (Twitter) feed grew during 2024 with regular activity; 47 posts during the year and currently 357 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, an unusually high figure.

Publications:

- EURO-CIU Newsletter: four articles
- British Association Teachers of the Deaf journal: CI Advocacy in Action
- *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 Advocacy in Action; Hearing across the lifespan
- *Canadian Audiology Journal*: CI SERVICES MATTER

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:

- Four members of the Board are members of the Steering Committee of the World Hearing Forum.
- 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.

- Influencing the Living Guidelines Recommendations ensuring that CI Users had a voice and that their issues and priorities were included in the final recommendations which are now disseminated in our presentations
- Increased invitations to participate in conferences about the activities of the network
- The increased reach, involving major international organisations, and website activity.

The community at CIICA is a beautiful and incredible thing to be a part of.

Looking to the future

CIICA's Board and consultants are working on the priorities for its Business Plan for 2025 onwards to sustain CIICA.AISBL as a growing and effective network for promoting access to CI and advocating for lifelong CI services for all who need them. The CI Advocacy Conference provided increased evidence of the network's advocacy activities and increased examples of the effectiveness of many of the members and organisations within the CIICA network. The discussions there provided impetus for further CIICA initiatives in 2024 and increased the volunteers who lead our activities.

Our members through our global survey, and through the active participants in our Conversations tell us that our advocacy message should be about "sustainable lifelong services which are person and family centred." This will be the focus of the second CI Advocacy in Action conference in October 2025.

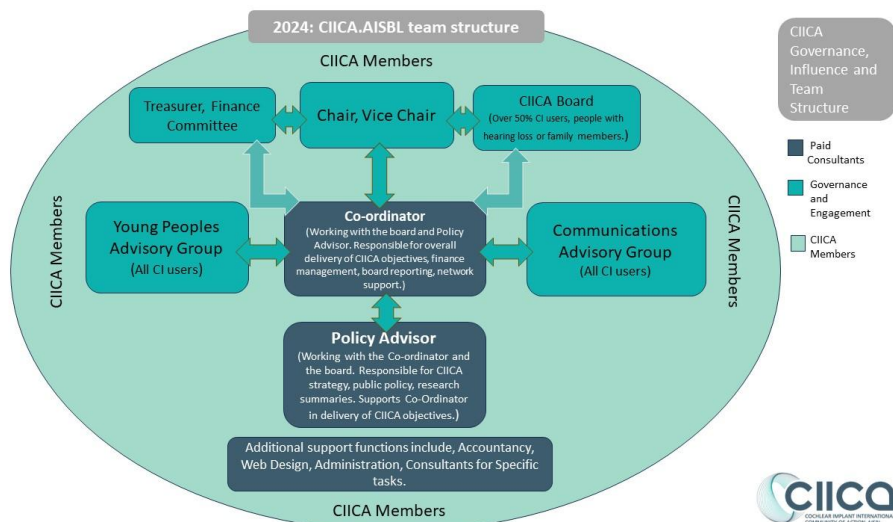
With thanks to all for their support and enthusiasm; we look forward to 2025.

Leo De Raeve, Brian Lamb and Sue Archbold, on behalf of the CIICA team

The CIICA Board together for the first time!



CIICA TEAM STRUCTURE 2024:



CIICA TEAM:

International Board:

Teresa Amat, Parent, Speech Therapist, Past 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

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

Ruth Warick, HA user, President, Canadian Hard of Hearing Association, BC Chapter, Canada

Communication Group:

Anita Grover, CI user, Chief Executive AVUK

Lise Hamlin, CI user, Past 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

With thanks to support from: Advanced Bionics, Cochlear, Earned income from activity, Private donations, Research grant from Social Sciences and Humanities Research Council, Canada and from AICE, Spain.

Further information:

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 \(ciicanet.org\)](#).