

CIICA.AISBL GENERAL ASSEMBLY
Friday 9 May 2025
Online: ZOOM room

Attended:

Board members: Leo De Raeve, Ruth Warick, Qais Khan, Darja Pajk, Teresa Amat, Eddie Mukaaya, Barbara Kelley, Lee Schoushkoﬀ, Paige Stringer

Full members: Anita Grover, Robert Mandara, Lise Hamlin

Apologies : Harald Seidler

Chair: Leo De Raeve

Community Members : Tricia Kemp, Rachel Cooper, Elif Ce, Lidia Best, Jarle Franceus,

Apologies: Kris English, Monika Lehnhardt, Tanya Saunders, Connie Mayer, Henk Vanrees

Facilitating: Sue Archbold, Coordinator, and Brian Lamb Public Policy Advisor, Suzy Link, Administrator, Captioning available

Agenda:

- Apologies
- Welcome Board and Full Members
- Welcome Community Members to observe
- Minutes of last meeting to be agreed
- Review of 2024, including end of year accounts to be legally submitted
- Approval of end of year accounts
- Approval of the current Board
- Business Plan for 2025
- Confirm Budget for 2025
- Next GA

Introduction

Leo De Raeve welcomed the Board and Full Members, and the Community Members who attended as observers. He explained that Lise Hamlin was resigning as a Full Member and the meeting thanked Lise for all her support for CIICA, particularly at the outset.

The minutes of the previous meeting (2024) were unanimously approved.

He reminded the meeting of the Vision and Goals of CIICA.AISBL:

Vision:

- CIICA is led by users and family groups, working closely with professional organisations, experts in the field of CI and other stakeholders to increase access to cochlear implantation and lifelong support for those who could benefit from them.

CIICA achieves this by:

- Raising the international global awareness of the health, social and economic benefits of cochlear implants for those who could benefit from implantation, health care practitioners and wider society.
- Empowering user led advocacy and awareness raising activity to influence governments and health funders to invest in addressing the under provision of CIs and other implantable technologies, related to habilitation, after care and upgrades.
- Supporting CI advocates with the tools they need to achieve this change.

He also emphasised that CIICA functions as a network:

- 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.

Governance

Leo reported that issues related to the Governance of CIICA:

- 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.

Finance Report

Ruth Warick, Treasurer, summarised the end of year (December) accounts for 2024, prepared by our accountants, JP Gilissen, for submission to the National Bank of Belgium. Our bank accounts are held by KBC International, with signatories Ruth Warick, Leo De Raeve, Chair, Harald Seidler (Vice Chair) and Sue Archbold (Co-ordinator). Two signatories required under 5K Euros, and three over 5K.

The full accounts were available for Full Members and Ruth Warick shared a break down and then summary:

Summary of income and expenditure for year ending Dec 2024:

Income	133,854€
Carried forward from previous year	25,609€
Expenditure	122,515€
Total Assets	36,984€

She reported on our funding sources: Cochlear, Advanced Bionics, Canadian social research fund, earned income, donations.

In response to a question from Robert Mandara about income for the Brussels conference, he was informed that sources were ticket sales, exhibitors' fees and grant income.

Ruth went on to comment about CIICA plans for Sustainability:

- 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 an 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.

Review of 2024

Brian reviewed the website growth over the year:



- As at end of December 2024 we have 639 (increase 23%) individuals and 122 organisations in our community representing activity in 74 countries across the globe.
- The largest group of individuals is CI users.
- New countries represented include Bolivia, Ecuador, Uruguay and Thailand.

Activity	2024	2023	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

Suzy showed the infographic developed which summarises the progress of 2024 in a visual format.



CI ADVOCACY IN ACTION

CIICA held its first in person conference in May 2024: CI Advocacy in Action.

We welcomed 100 delegates to Brussels, 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.

The conference had extremely high ratings:

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

“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 had led to many ongoing collaborations and the discussions on the Talking Wall been used as topics for CIICA Conversations.



CIICA developed two types of online events:

CIICA Live with presentations, and CIICA CONVERSATIONS, small group conversations with a specific topic. The Conversations are becoming active groups to initiate change on individual themes.

CIICA LIVE EVENTS:

- **CI Advocacy in Action**
- **CI in low and middle-income countries**

Themes of CIICA CONVERSATIONS:

- Person Centred Care in Adult CI Services
- Young Adults with CI
- Tinnitus & CI
- Issues for parents

All events available on website with captions and summaries of the Conversations are available as resources and are becoming used as sources of evidence. Anita Grover was thanked for her suggesting these important events.

Resources

- A Practical Guide for Advocacy was launched at our Conference – with guidance, examples, and videos of advocacy tips to support the network.
- All resources are available as downloads. Other resources include regular research updates.
- Briefings on our research on adults and young adults
- CI and Literacy – Briefing paper
- Summaries of all the Conversations to be available as evidence
- Presentations from CIICA LIVE events available
- 3.2K downloads of our resources in 2024.

Research

Young Adults with CI Matter:

Data from the adult survey was broken down to show the first group to receive CI as children and growing up as both deaf and hearing. A report, video and summary briefing were produced as advocacy tools.

- *"CI has surely modernised the concept of deafness".*
- *"I've always heard through a cochlear - so it's all I know".*

Young Adults with CI Services Matter: Briefing from the global adult survey:

A Briefing from the young adults' global survey, Young Adults with CI MATTER was developed as an advocacy tool following the full report: [Young Adults with CI Matter: CIICA's New Report to Share! – CIICA](#) Support from AICA, Spain.

Research grant from Social Sciences and Humanities Research Council, Canada, via York University, Toronto, with the Principal Investigator, Professor Connie Mayer.

Communication with others during the year

- Communication within the network is ongoing with biweekly CIICA Updates: 50% open rate
- Sharing of activities on the website
- International CI Day
- World Hearing Day: WHO
- With members for specific activities EG First Voice, British Cochlear Implant Group, EUROCIU
- Sharing advocacy work by members: government visits
- As a member of the World Hearing Forum
- International Federation of Ageing
- Published papers: The Hearing Journal, ENT and Audiology News

Conference attendances

There was increasing conference attendance during the year, sharing CIICA Activities, research and resources globally.

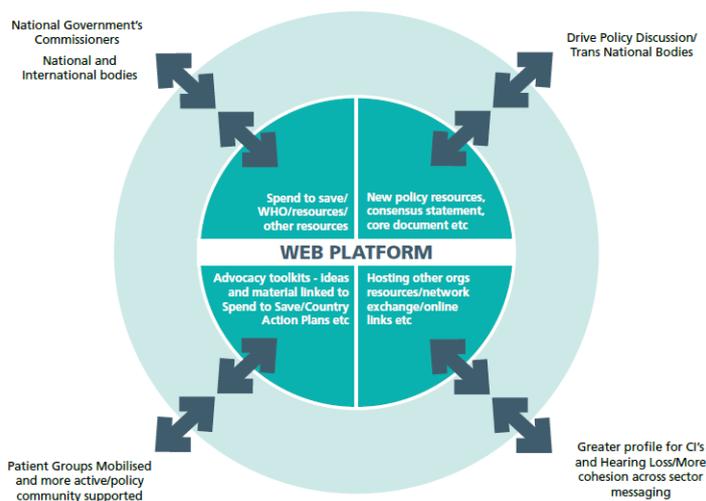
Looking to 2025:

Business Plan for 2025:

The business plan for 2025 had already been shared with its four areas of activity:

- **Governance:** working to the legal obligations as CIICA.AISBL
- **Funding and Sustainability:** to develop diverse sources and work for sustainability, using the support of increasing numbers of volunteers
- **Development and Support of the Network:** using the website as a hub of support
- **Developing Policy and Evidence** to support advocacy activities

The website as the hub of support and action:



Brian took the meeting through the website platform being the hub of support and action as was envisaged from the outset. The website is constantly updated, including Member news.

Conversations planned for 2025

Developing the lived experience into evidence.

Themes important to CI users and families including:

- Person Centred CI Services
- Education Issues for Children with CI
- Young Adults with CI
- CI in Older Adults
- CI in Low and Middle-Income Countries
- CI and Remote service delivery
- Funding bilateral CI for adults
- CI and Tinnitus
- Advocacy in Action

Finance for 2025

Summary budget for 2025 (Euros)

Ruth Warick presented the budget for 2025 and commented that to date we are working to budget, with the conference income and expenditure being the largest items this year.

Predicted income:	82,800
Predicted conference income:	55,000
Total predicted income:	137,800

Predicted expenditure:	79,002
Predicted conference expenditure:	55,000
Total predicted expenditure:	134,002

Predicted net surplus	3,798
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Carried forward from 2024: (adjusted for payments in advance)	35,370
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Predicted end of year assets:	39,168€
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It was also pointed out that the ongoing costs of being a legal entity are rather more than previously, including insurance, belonging to Brussel's organisations, our legal address, higher bank charges, accountancy and legal costs.

Anita Grover queried that the planned budget did not show increased income to meet increased planned activity. It was explained that this was a conservative budget but ongoing discussions for increased funding and grants were taking place and there was confidence that CIICA would continue to increase activity, with the support of volunteers.

Business Items:

The Full Members unanimously confirmed:

- The accounts presented for 2024
- The present Board, with Leo De Raeve as Chair, Harald Seidler as Vice Chair and Ruth Warick as Treasurer
- Budget presented for 2024

Summary

Leo thanked everyone for the positive interactions during the GA and for all their work to make CIICA.AISBL a reality and their individual advocacy work for CI and to the Communication Group joining the Board as Full Members of CIICA.AISBL. We look forward over the next year to increased activity and collaboration across the globe.