

CIICA.AISBL GENERAL ASSEMBLY

Friday 10 MAY 2024

Brussels

Attended:

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

Invited Board Member: Paige Stringer

Full members: Anita Grover, Robert Mandara

Apologies : Lise Hamlin

Chair: Leo De Raeve

Facilitating: Sue Archbold, Coordinator, and Brian Lamb Public Policy Advisor; Captioning available

Agenda:

1. Welcome
2. Review of 2023
3. End of Year accounts for 2023
4. Approval of the current board
5. New Board Member
6. Business Plan for 2024
7. Confirm Budget for 2024
8. Next GA

Introduction

Leo De Raeve welcomed the Board and Full Members, and the 43 Community Members who attended as observers. He explained that we became a legal entity on 8 Feb 2023 and this was therefore our first GA, in our legal home: Maison Associations Internationale, Rue Washington 40, 1050 Brussels. 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.

Finance Report

Ruth Warick, Treasurer, summarised the end of year (December) accounts for 2023, 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 attendees and Ruth Warick shared the summary:

Summary of income and expenditure for year ending Dec 2023:

- | | |
|---|---------------------|
| • Income: | 71, 525 Euros |
| • Carry forward from previous year: | 22,277 Euros |
| • Expenditure: | 68,193 Euros |
| • Carried forward to 2024: | 25,609 Euros |
| • Sum received in advance for 2024: | 18,089Euros |
| • Total assets as at 31 Dec 2023 | 45,448 Euros |

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

Review of 2023

Sue Archbold, Co-ordinator, shared a review of the year, which indicated a 20% growth in members to 556 individuals and 109 organisations from 66 countries. It also indicated a corresponding growth in website activity.

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:

- 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

Themes of CIICA CONVERSATIONS:

- Person Centred Care in CI Services
- Young Adults with CI
- Tinnitus
- Consulting on the Living Guidelines
- Why Parents' Groups?

All events available on website with captions and summaries of the Conversations are available as resources and becoming sources of evidence.

Resources

A range of resources are developed and shared on the website: 2,500 downloads

- CIICA Summary of the Living Guidelines 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 \(ciicanet.org\)](https://ciicanet.org/ciica-summary-of-the-living-guidelines-for-adult-ci)
- **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 \(ciicanet.org\)](https://ciicanet.org/ci-services-matter-briefing-web-final-2.pdf)

Communication with others during the year

- Communication within the network is ongoing with regular CIICA Updates
- Sharing of activities on the website
- International CI Day
- World Hearing Day
- With IFHOH Young People
- 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, Int Jnl Audiology

Conference attendances

In addition to regional attendances, presentations were made at:

- British Cochlear Implant Group
- European Symposium on Paediatric Cochlear Implantation, Rotterdam

Research

Cochlear Implants in Deaf and Deafened adults: a global consultation on lifelong aftercare Research grant from Social Sciences and Humanities Research Council, Canada, via York University, Toronto, with the Principal Investigator, Professor Connie Mayer. Over 1000 responses from 30 countries, which resulted in a report and Briefing which is now widely used to support advocacy work.

Examples of impact during the year:

- Our Children's Briefing to influence the provision of children's services eg in Australia
- Our report CI SERVICES MATTER: Providing Evidence for Advocacy - eg *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: *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 issues included
- 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.
- Published papers eg *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

Looking to 2024:

Business Plan for 2024:

The business plan for 2023 had already been shared with its four areas of activity:

- **Governance**
- **Funding** : to develop diverse sources and work for sustainability
- **Development and Support of the Network:**
- **Developing Policy and Evidence**

Finance for 2024

Summary budget for 2024 (Euros)

Ruth Warick presented the budget for 2024, attached, and commented that to date we are working to budget, with the conference income and expenditure being a new item this year.

Predicted income: 81,175

Predicted conference income: 43, 500
Carried forward from 2023: 25,609
(adjusted for payments in advance)

Total predicted income: 149,744

Predicted expenditure: 79,071
Predicted conference expenditure: 43,464

Total predicted expenditure: 122,535

Predicted end of year assets: 27,749

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.

New Board Member

It was proposed by Harald Seidler that Paige Stringer, CI User, Founder and Chief Executive of Global Foundation for Children with Hearing Loss, of 19905 4th Avenue, #D Poulsbo, USA, become a member of CIICA's Board. The Board had received the application from Paige Stringer, and all Board members agreed she will become a member of the CIICA Board.

Business Items:

The Full Members unanimously confirmed :

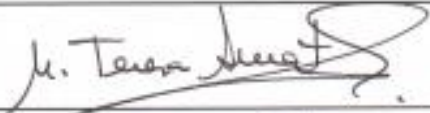

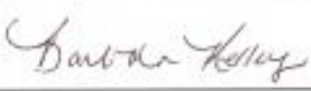
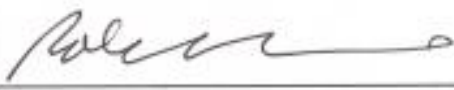
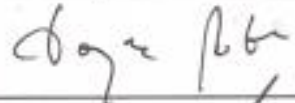



- The accounts presented for 2023: moved by Ruth Warick, supported by Lee Schouskoff
- The present Board, with Leo De Raeve as Chair, Harald Seidler as Vice Chair and Ruth Warick as Treasurer
- Budget presented for 2024
- The appointment of Paige Stringer to the Board

Summary

Leo thanked everyone 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 .

GENERAL ASSEMBLY REGISTER

MAY 2024

NAME	SIGNATURE
Teresa Amat	
Leo De Raeve	
Anita Grover (Full Member)	
Barbara Kelley	
Qais Khan	
Robert Mandara (Full Member)	
Eddie Mukaaya	
Darja Pajk	
Lee Schoushkoff	
Harald Seidler	
Paige Stringer	
Ruth Warick	