

PROGRAMME



OUR 2ND GLOBAL CONFERENCE:

CI ADVOCACY IN ACTION

Advocating for sustainable lifelong CI services.

OCTOBER 16/17, 2025

BRUSSELS



WHERE SCIENCE MEETS EXPERIENCE

Welcome

It is a pleasure and great honour to welcome you to the second CIICA Conference on 'CI Advocacy in Action 2025'.

Building on the impact of our first global conference in May 2024 in Brussels, our second conference will bring together the network of CI users, families, professionals, academics, industry and policy makers and funders from across the globe together to share our advocacy goals.

With funding and resource challenges globally how do we ensure that those who could benefit from CI can gain access, and those who have CI have the lifelong sustainable services required? These issues will be addressed in a lively and vibrant two days, in this unique inclusive conference, learning from each other and building collaboration across the globe.

Our CIICA global network continues to grow, with members inspiring each other to action to ensure maximum benefit from this amazing technology. Do use this conference to get to know others, to make useful contacts, and help us build the CIICA network to be even stronger and more active. The success of the conference is up to all of us – and do enjoy it!



Dr Leo De Raeve
Chair, CIICA



CIICA was established in 2021 as a result of a stakeholder meeting in Geneva, 2019, and a global consultation about the best way to address the gap in provision for CI. CIICA was designed as a network, with organisation and individual members, with the goals:

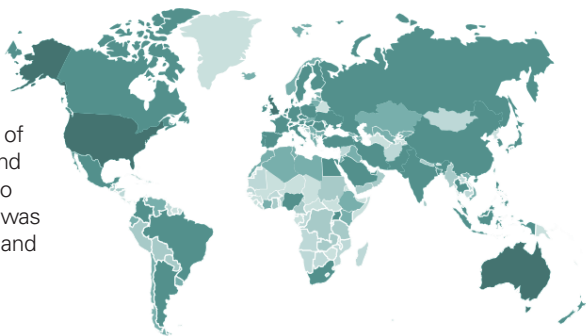
To develop a global community of CI advocacy groups, with opportunities to share activities and resources and collaborate to strengthen the user and family voice

To provide CI advocates with the tools for change they need to increase access to CI services

To increase access to the provision of CI and lifelong services globally.

If you are not yet a member, do join us.

It is free and enables you to share in this global active community.



CIICA has grown steadily and now has 712 individual and 127 organisation members in 76 countries.

The largest group of members are CI users and families, and members include audiologists, ENT specialists, therapists, educators, other professionals, industry and public policy specialists and researchers. These groups are represented here today at our second Global Advocacy Conference. CIICA offers online events with expert presentations and CIICA Conversations where small groups focus on specific topics of shared interest, and develop and share advocacy resources.

Our second CI Advocacy in Action Conference: Where Science Meets Experience

The CIICA Team – welcome you to our second advocacy conference, held at our legal home – Maison des Associations Internationales, Brussels.

We have an exciting range of delegates from across the globe: the programme is full, and deliberately has no break out workshops so that we can all share the same messages. We will hear of the amazing advocacy activities taking place even in challenging situations and learn from each other, as well as from experts in advocacy. You will hear about the collaborations which arose after last year's conference and the impact made.

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.

A delegate from last year

Once more we have our Talking Wall where all can contribute thoughts and questions and suggest action. Last year our online events and resources were based on the emerging issues in the Talking Wall.

In this way, those who can't attend can be involved; some of those who can't attend have provided information on their advocacy work in the rolling slide show, and do use lunch and coffee breaks to visit the exhibitors and look at the rich varied information in your pack from our network. This year SLIDO will also be used to obtain your comments resulting in a report from the conference.

Our Conference begins with a welcome from some of the CIICA team and Founding Members. The CIICA Board and team will be delighted to talk to you at any time, and we are grateful to those who contribute to the increasing impact of the CIICA network. In our challenging world, the collaboration between CI users, families, professionals and industry is needed more than ever to ensure that lifelong, sustainable CI services become a reality, wherever you are.

Speakers include:



Rob Beenders
Belgian
Minister



Zala Tomasic
Member of
European
Parliament



Sara Rubinelli
Professor
of Health
Communication,
Lausanne



**Dr Shelly Chadha
& Dr Carolina Der**
World Hearing Forum,
WHO



**Astrid van
Wieringen**
President,
International
Society of
Audiology



**Prof Graeme
Clark**
CI Pioneer &
founding
member of
CIICA



Michal Luntz
CI User and
CI Surgeon

THE PROGRAMME

THURSDAY 16 OCTOBER - DAY 1

08:30 Coffee and Registration / Exhibition

09:30 Welcome

CHAIR: Leo De Raeve

Leo De Raeve, Harald Seidler, Eddie Mukaaya, Monika Lehnhardt, Sue Walters

Shelly Chadha: *WHO, Welcome from Geneva*

Graeme Clark: *Welcome from Melbourne*

Rob Beenders: *Belgian Minister & CI User*

Zala Tomasic, MEP: *Political Experience and Personal Story*

10:15 Intro to SLIDO, Who are you? Daniel Asplin

10:30 Coffee, Exhibition and Chat

11:00 Influencing Governments

CHAIR: Sue Archbold

Anita Grover and Tori Bishop Rowe: *What Works, What Doesn't & Why It Matters*

Teresa Amat: *Influencing the Spanish Parliament*

Katalin Gal: *Changing policy in Romania: getting the evidence*

Paul van de Heyning & Patrick D'Haese: *Hearing Health Forum EU increasing access to CI*

Mark Laureyns: *Influencing Governments: getting the numbers right*

Bowen Tang: *Developing a CI Report Card in Canada: Patient & Professional Partnership*

Lee Schoushokoff: *Hearing our Future: How CI consumers can drive change*

CIICA Collaborations: Our Global Impact / Group Photograph

12:30 Lunch / Exhibition / Activities & Discussions

13:30 CIICA: Where Science meets Experience

CHAIR: Astrid van Wieringen

Tobias Fischer: *Science in My Life: Living Well with CI Requires More Than Surgery*

Harald Seidler: *Where Science Meets Rehabilitation for Adults*

Steph Halder: *For Children: taking the technology into education*

Michal Luntz: *Essential information for candidates and users: how to offer it*

Agata Mikusek: *How my work helped me come to terms with my hearing loss*

Brian Cleary: *Experiences as a Researcher with a Cochlear Implant*

14:45 Coffee, Exhibition and Chat

15:15 CI in Low Resourced Countries

CHAIR: Paige Stringer

Paige Stringer: *Introduction: The continuum of care*

Carolina Der: *Ear and hearing care program for school students in Chile*

Ekaterine Tortladze, Teona Gvalia: *Building Hearing Care into Georgia's Health System*

Steve Kittur: *CI & Assistive Technologies: Kenya's Emerging Experiences*

Lusine Stepanyan: *Strengthening the CI Community in Armenia.*

Vahishtai Daboo: *Dealing with numbers*

Tanya Saunders: *Advancing Awareness: what YOU can do*

16:40 SLIDO discussion

17:00 Close

19:00 Networking Supper

La Cocina Rue Washington 149, 1050 Bruxelles, Belgium (squadracocina.com)

Due to popularity this supper is fully booked.

FRIDAY 17 OCTOBER - DAY 2

09:00	Good Morning!	Daniel Asplin
09:15	Parents as Advocates	CHAIR: Eddie Mukaaya
	Parents are the real deal! <i>Giovanna Troncoso: I got the lead role without auditioning!</i> <i>Marcela Varela Vargas: When a child listens a family dreams</i> <i>Asel Mairambekova & Zhanarkul Iiebaeva: Moving on in Kyrgyzstan</i>	
	New developments <i>Paul Sommers: Genetic Testing for Hearing Loss</i> <i>Geraldine Honnet: Gene therapy information for families</i>	
	Parents fighting for education <i>Leona Pejcharova: Resources for schools</i> <i>Liubov Wolowik: Educating the educators</i> <i>Connie Mayer: Where Science Impacts Literacy</i>	
10:30	Young People with CI: Agenda for Change	
	<i>Qais Khan, Melis Durmaz Yildirim, Marie Stocklova, Raquel Tiana, Elaine Mukaaya, Nehir Özdemir, Bowen Tang</i>	
11:00	Coffee, Exhibition and Chat	
11:30	Adults: Advocating for Lifelong Services	CHAIR: Barbara Kelley
	<i>Lidia Best: Access to lifelong services: how and why?</i> <i>Nikki Philpott: Towards personalised adult services</i> <i>Elmar Haacke: Self-Help Groups - An important partner for successful aftercare. Why do we need them ?</i> <i>Francesco Pavani: Binaural hearing for all: the importance of listening with two ears</i> <i>Darja Pajk: Stereo Hearing – From Magic to Mastery</i> <i>Cathy Birman: Cochlear implants – you are never too old!</i>	
12:45	Lunch / Exhibition / Activities & Discussions	
13:45	Delivering Services Differently	CHAIR: Holly Teagle
	<i>Henk van Rees: The Echo of Experience: in the Living Room</i> <i>Jantien Vroegop: Towards future-proof CI healthcare: transforming the CI intake process into a one-day journey</i> <i>Kirby van As: CI journey supported by resources</i> <i>Helen Cullington: Wherever you are, we're there too: remote CI care</i> <i>Holly Teagle: Expanding CI service delivery options in New Zealand</i> <i>Carolina Der: Approach to service delivery and cochlear implants in LMICs</i>	
15:00	Coffee	
15:30	Advocacy: What do we need?	CHAIR: Leo De Raeve
	<i>Brian Lamb: New Briefing – Investing in our Hearing Improves Lives and is Cost-effective. How to advocate for more investment in CIs</i> <i>Sara Rubinelli: The next leap: Turning growth and advocacy into lasting resources for CIICA</i>	
16:15	Summary Reflections	
	<i>What are you doing on Monday?</i>	
16:45	Close	CHAIR: Leo De Raeve



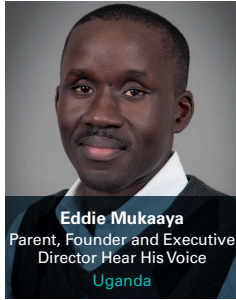
Leo De Raeve PhD
Director of ONICI,
Scientific Advisor to EURO-CIU
Belgium



Lee Schoushko
Chief Executive NCIT,
PINDROP Foundation
New Zealand



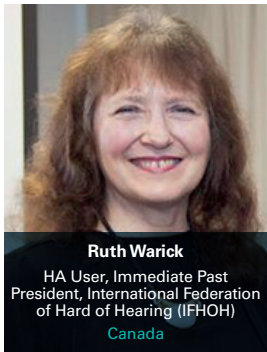
Teresa Amat
Parent, Speech Therapist,
Immediate Past President
European Association of
CI Users (EURO-CIU)
Spain



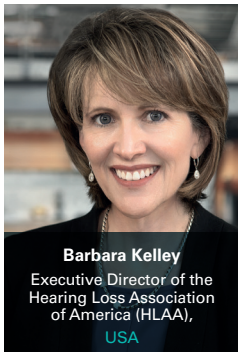
Eddie Mukaaya
Parent, Founder and Executive
Director Hear His Voice
Uganda



Harald Seidler
MD, CI User & ENT Specialist, DSB
Germany



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



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
Slovenia



Qais Khan
CI User and Advocate
UK



Paige Stringer
CI User, Founder and
Chief Executive of Global
Foundation for Children with
Hearing Loss
USA



Invited Member of the Board:

Cathy Birman
ENT Professor, CI Surgeon
Australia

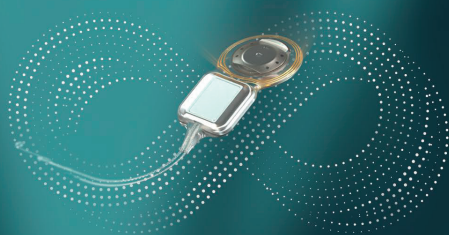
PINDROP

Every Word Matters. Every Voice Counts.

The Pindrop Foundation is proud to sponsor captioning at the
Global CI Advocacy Conference

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This material is intended for health professionals. If you are a consumer, please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always read the instructions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information. Cochlear, Hear now, And always, Nexa, Nucleus, and the elliptical logo are either trademarks or registered trademarks of the Cochlear group of companies.
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Call for a European Hearing Health Strategy

The Hearing Health Forum EU, together with MED-EL, EURO-CIU, and HEARRING, calls on European policymakers to establish a comprehensive European Hearing Health Strategy, grounded in the **HEAR** pillars:

- **H**earing Loss Awareness
- **E**arly Detection and Prevention
- **A**ccess and Care
- **R**esearch and Data

Add your voice and
endorse the Manifesto
on Hearing Health



HEARING HEALTH FORUM EU

MED-EL



hearing



*Free Listening
Practice &
Support Tools*



HearingSuccess

Accessibility



Captioning will be provided in English, French, German, Dutch and Spanish.



Technology support has been provided by Sennheiser and by Phonak and we are very grateful.

CIICA Advocacy Resources

If you go to www.ciicanet.org/resources you will find a list of our advocacy resources to download – if you wish to translate any, then just ask!

You will find some in your conference pack.

Support for our Conference

We are very grateful for all support for our conference, for our speakers and contributors, for those who have been enthusiastic in the planning and have volunteered their help and support to make it possible for a wide range of stakeholders to attend. Supporters include:



Deutsche Cochlea Implantat
Gesellschaft e.V.



European Academy of Otolaryngology and Neurotology



Social Sciences & Humanities
Research Council, Canada



www.ciicanet.org