

Welcome to CIICA LIVE! The World Report on Hearing: What next for CI Advocacy?

Starting 7pm UK time

May 5/6 2021

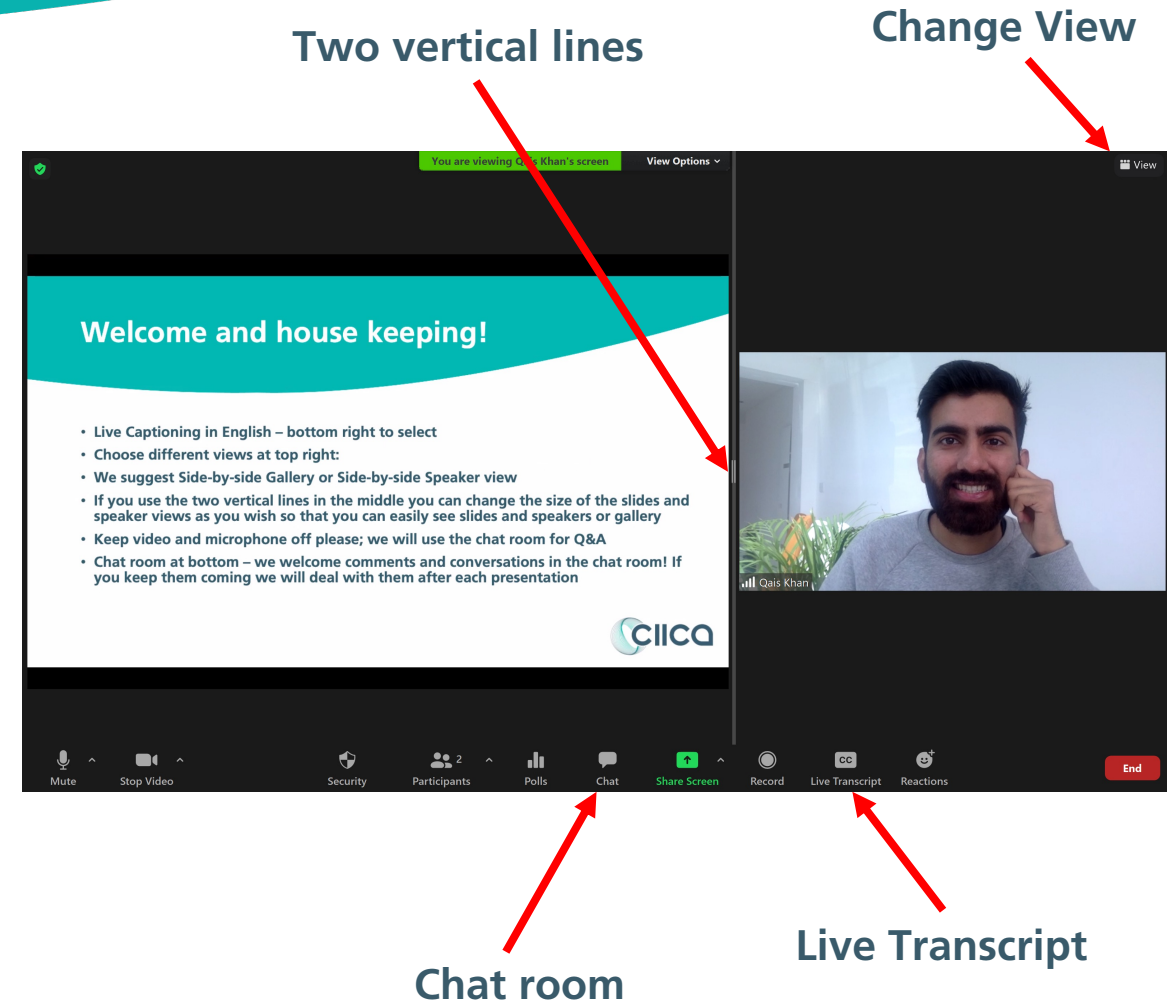
Chair: Leo De Raeve, Acting Chair of
CIICA

Speakers: Sue Archbold, Cathy Birman,
Beatrice Cusmai, Brian Lamb, Eddie
Mukaaya, Paige Stringer



Welcome and house keeping!

- Live Captioning (Transcript) in English – bottom right to select
- Choose different views at top right:
- We suggest Side-by-side Gallery or Side-by-side Speaker view
- If you use the two vertical lines in the middle you can change the size of the slides and speaker views so that you can easily see slides and speakers or gallery
- Keep video and microphone off please; we will use the chat room for Q&A
- Chat room at bottom – we welcome comments and conversations in the chat room!





The Foundation of CIICA: CI International Community of Action

Leo De Raeve

Acting Chair of CIICA

Scientific Advisor EURO-CIU

Director ONICI

Zonhoven-Belgium

<http://www.onici.be>

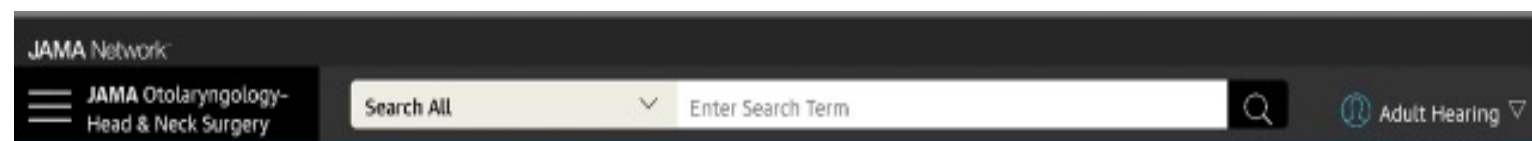
Leo.de.raeve@onici.be



International Consensus paper

Who was involved in the process?

- 31 Audiologists and ENTs across 13 countries
- A Steering Committee: Professor Craig Buchman (chair-US), Thomas Lenarz (Germany), Professor Rene Gifford (US), Dr. David Haynes (US) and Professor Gerard O'Donoghue (UK)
- Consumer & Professional Advocacy Committee (CAPAC) asked to comment on the Consensus Statements



This Issue Views 4,999
[Review](#)
August 27, 2020

JAMA Otolaryngology-Head & Neck Surgery

[Full Text](#)

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The Most Talked About Articles of 2020

Unilateral Cochlear Implants for Severe, Profound, or Moderate Sloping to Profound Bilateral Sensorineural Hearing Loss
A Systematic Review and Consensus Statements

Craig A. Buchman, MD¹; René H. Gifford, PhD²; David S. Haynes, MD²; [et al](#)

[Author Affiliations](#)

JAMA Otolaryngol Head Neck Surg. 2020;146(10):942-953. doi:10.1001/jamaoto.2020.0998

**JAMA NETWORK
ARTICLES OF THE YEAR
2020**





The Consumer & Professional Advocacy Committee (CAPAC) asked to comment on the Consensus Statements

- CAPAC stressed that **promotion and advocacy** will be very important
- The **perspectives of CI-users** must be taken into account (client-centered care)
- The CAPAC plus other important organizations representing CI-Users and CI professionals: **would like to focus on 'awareness' and stressed the need for adult hearing screening and for good standards for (re)habilitation and aftercare.**
- Remarks and suggestions of CAPAC were integrated in the report, but **not in the publication.**

It illustrates why it is **so important to strengthen the advocacy platform of user organisations**, so there is not only focus on surgery and audiology, **but also on client-centered (re)habilitation, quality of life and the well-being of CI-users.**

- A meeting in Geneva, Dec 2019, led to consultation on global advocacy for CI by Brian Lamb and Sue Archbold

Next Step = Action!

The Cochlear Implant International Community of Action (CIICA) was formed in February 2021 – not a new organization – a community or network

www.ciicanet.org

CIICA'S 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 services.
- To increase access to the provision of CI and lifelong services globally

We already have 250 individuals and 55 organisations from 39 countries



Community Members

Welcome to the new and developing CIICA community – we are just starting our conversation together! All who share our goals and values are welcome to join.

We offer a trusted space to share conversations, advocacy activities, resources, research and inspire each other and we look forward to seeing the community grow and evolve. The content in these sections will grow as you contribute.

If you haven't joined us yet, you will need to register to access the pages: [join here](#).

See [here](#) for information on our members as at March 31, 2021.



[HOME](#) [ABOUT US](#) [JOIN](#) [NEWS](#) [RESOURCES](#) [COMMUNITY MEMBERS](#)



WELCOME

CIICA provides an opportunity for a new way of working for cochlear implant advocacy groups and individuals, with opportunities for sharing and collaboration.

“Hearing loss has real health consequences and a huge economic impact on individual and society – we need to take action – we have a story to tell...”

CIICA'S GOALS

We aim to close the gap in Cochlear Implant provision and ensure lifelong support for all who could benefit.


[Read More >](#)

JOIN OUR GLOBAL COMMUNITY

Join our global community to improve cochlear implant provision. This will give you access to our Community Members area where you can share advocacy news, issues, resources and research.


[Join Here >](#)

LATEST NEWS


New evaluation concludes there is not enough evidence to recommend hearing screening for adults in the US.


[Read More >](#)

What's new on the website for our global CI Advocacy Community? See below and [join up](#) if you haven't already and join the 55 organisations and 230 individuals already part of CIICA.


EVENTS

In the Events section you will find information about CIICA events and also about relevant events that others are holding which may be of interest.


[Learn More >](#)


COMMUNITY ADVOCACY NEWS

See links to the latest advocacy news in our CI community. Email info@ciicanet.org if you have something interesting to share.


[Learn More >](#)


CURRENT ISSUES

Join debates on the issues of the day. Have your say! Join the discussion!


[Learn More >](#)


ADVOCACY RESOURCES

A selection of resources to use in your advocacy work; we look forward to adding more. Please send suggestions of resources you find useful.


[Learn More >](#)


RESEARCH ROUNDUPS


Here you can find summaries of the latest published papers and their implications for advocacy work.


[Learn More >](#)

CAN YOU HELP?


Have you got a problem in your advocacy work to share? Do you need some evidence or to ask someone how they did it? or to ask where you find some information you need?



[Learn More >](#)



ACTIVE RESEARCH

Here you will find links to ongoing relevant research – so that we all can share what is going on! You will find here opportunities to participate in research to help advocacy work.


[Learn More >](#)



Go to our developing website: the hub of the community...

Thanks to our [website group](#): Anita Grover, UK, Robert Mandara, Finland, Lise Hamlin, USA, Qais Khan, UK

Welcome to the Steering Group of CIICA!



Teresa Amat
President European Association
of CI Users (EURO-CIU)
Spain



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



Qais Khan
CI user & advocate
UK



Eddie Mukaaya
Founder & Executive Director
Hear His Voice
Uganda



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



Lee Schoushkov
Chief Executive NCIT,
PINDROP Foundation
New Zealand



Ruth Warick,
President, International
Federation of Hard of Hearing
(IFHOH)
Canada



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



Harald Seidler
CI User and ENT specialist,
DSB
Germany

Our programme for today...

- WELCOME TO CIICA LIVE.....Leo De Raeve
- The World Report on Hearing: development and key points for advocacy.....Paige Stringer
- The World Report on Hearing: key points for CI advocacy, launch of resources.....Sue Archbold & Brian Lamb
- Using the World Report – in Italy?.....Beatrice Cusmai
- Using the World Report – in Uganda?.....Eddie Mukaaya
- Using this great opportunity for CI advocacy: THE LAST WORD.....Cathy Birman

Our Speakers



Paige Stringer
Founder of the Global
Foundation for
Children with Hearing
Loss
USA



Sue Archbold
PhD, Co-Ordinator of
CIICA
UK



Beatrice Cusmai
VP of AGUAV, Secretary
of EURO-CIU
Italy



Eddie Mukaaya
Founder & Executive
Director Hear His Voice
Uganda



Cathy Birman
Medical Director,
Sydney CI Centre
Australia



Brian Lamb
OBE, Public Policy Advisor,
CIICA
UK

