

Meeting subtitles

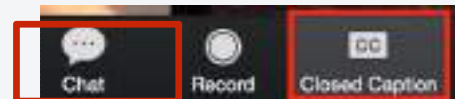
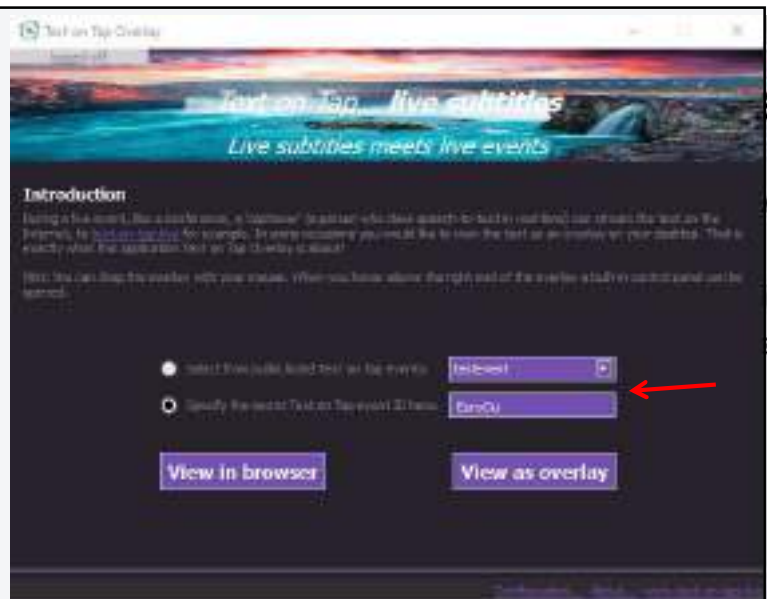
1. For English only: Directly in Zoom by turning on the closed captions (CC). Here you can adjust the size yourself.

For English and other languages

2. FULL SCREEN: Using the URL in your browser – link on the chat

3. LINES OVERLAY:

Download the Text on Tap overlay software. Link on chat.



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Speakers view to Lip Read

f t y 2



While in a meeting, you can switch between Active Speaker view and Gallery view.



You how you can change your screen from gallery overview to speakers view. Just look at the top right corner of your Zoom screen and switch to gallery or to speakers view



1.

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Welcome AGA 2020

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Hearingcare Access for all

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- **Member of EDF**
- **Member of the Platform**
- **Coalition Manifesto on Hearing Loss & Disability**
- **Coalition for Delphi guidelines**



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- **2020 meetings online to be present as much as possible**



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EURO-CIU
Chair

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AGA - Board Proposal:
Moderator Chair :
Leo DeRaeve
Moderator questions:
Brian Archbol
Secretary:
Beatrice Cusmai



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2.


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Rules for participants

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Rules for Web meeting participants

- Be on time.** We promise to start and end the meeting according to the times on the agenda.
- Be prepared.** Come to the meeting with a positive attitude. Please review the meeting agenda and any attached documents before the start of the meeting. Be prepared to discuss the issues and offer solutions.
- Everyone in the meeting is expected to **share ideas, ask questions, and contribute to the discussions.**
- To stay within the **time schedule**, a maximum of 2 questions/topic are possible during the meeting. Ask your questions through the chat box. Other questions will be answered later.



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Rules for Web meeting participants

- Silence means agreement.** If you remain silent, it means you agree.
- Do not multi-task.** Stay mentally present during the meeting.
- Your **microphone is muted** during the meeting. Background noise disrupts the meeting and discussions within a group of 55 participants is not possible. So **use the chat box.**
- Stick to the agenda. Please try to **stay focused.**
- Attack the problem, not the person. **No problem to have differences of opinion.** Honest and constructive discussions are needed to obtain the best results.



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3.



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Agenda

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GA Agenda 3/10/2020

1- WELCOME

2- Rules of the meeting

3- Approval of agenda

Collaboration with others:

4- CAPAC

5- CIICA

6- WHO WHF Member certification

7- WHO WHF Make listening safe

8- EDF news

9- MOSAIC

10- Hearing health forum

COVID:

11- COVID

a) Introduction

b) BRANDS TIME

c) Hospitalisation documents

d) Newsletter and website

e) Accessible Education

f) Communication masks CE

g) CI survey and repetition

Ongoing projects:

12 - CI statistics

13- 25th anniversary postponed

14- EURO-CIU 2021 Germany cancelled – new candidates 2022

15- EFW 2021

16- CI Day, logo and slogan approval 2021

17- Elections 2021

18- New project, Dementia Document like Spend2Save summary

19- Bullying and Cyberbullying with CI students

EURO-CIU visibility & work:

20- Reminder to display EURO-CIU logo

21- Apps and resources in English to our website

22- CI voices

23- Participation in website and newsletter

24- Report 2019/2020

25- Finances

26- Audit

27- Report 2019

28- Board discharge 2019

29- Open floor – Questions and answers time

30- Closure

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Collaboration with others

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Consensus paper and CAPAC

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Consensus paper + CAPAC

- International Consensus Paper on Adult Cochlear Implantation **published in JAMA Otolaryngology – Head & Neck Surgery (JAMA OTO)** on August 27, 2020 (earlier press release)
- Publication outlines international medical and audiological consensus **on minimum standards of care for unilateral adult cochlear implantation**
- Using a **Delphi consensus process** the ICP is designed to raise knowledge, set minimum standards of care and better define referral pathways: literature review, 3 voting rounds on several statements by 31 medical & audiological experts on CI.
- Keep the statements with a minimum of 75% agreement by all experts
- Result= 20 statements within 7 categories**
- CAPAC** (Consumer and Professional Advocacy Committee) could deliver their comments online + during Geneva meeting



Panel: 31 experts in medicine and audiology and cochlear implantation

Dr Oliver Adunka, Ohio State University, Columbus, OH, USA
 Dr Allison Blewer, AuD, Rocky Mountain Ear Center, Englewood, CO, USA
 Professor Robert Briggs, The University of Melbourne; Royal Victorian Eye and Ear Hospital; Royal Melbourne Hospital, Australia
 Dr Matthew Carlson, Mayo Clinic School of Medicine, Rochester, MN, USA
 Dr Pu Dai, PLA General Hospital, Beijing, China
 Dr Colin Driscoll, Mayo Clinic School of Medicine, Rochester, MN, USA
 Dr Howard Francis, Duke University School of Medicine, Durham, NC, USA
 Dr Bruce Gantz, University of Iowa Health Care, Iowa City, IA, USA
 Dr Richard Gurgel, University of Utah Hospitals and Clinics, Salt Lake City, UT, USA
 Dr Marlan Hansen, The University of Iowa, Iowa City, IA, USA
 Associate Professor Meredith Holcomb, Medical University of South Carolina, Charleston, SC, USA and University of Miami, FL, USA
 Dr Eva Karlborg, Karolinska University Hospital, Stockholm, Sweden
 Dr Milind Kirtane, Seth GS Medical College and KEM Hospital, Parel, Mumbai, India
 Ms Jan Larky, Stanford University School of Medicine, Stanford, CA, USA
 Professor Emmanuel Mylanus, Radboud University Medical Center, Nijmegen, Netherlands

Dr Thomas Roland, New York University School of Medicine, New York, NY, USA
 Professor Shakeel Saeed, University College Hospital, National Hospital for Neurology and Neurosurgery; Royal National Throat, Nose and Ear Hospital, London, UK
 Professor Henryk Skarzynski,* Institute of Physiology and Pathology of Hearing, Warsaw, Poland
 Professor Piotr Skarzynski,* Department of Teleaudiology and Screening, World Hearing Center, Institute of Physiology and Pathology of Hearing, Warsaw/Kajetany, Department of Heart Failure and Cardiac Rehabilitation, Medical University of Warsaw; Institute of Sensory Organs, Kajetany, Poland
 Dr Mark Syms, Arizona Hearing Center, Phoenix, AZ, USA
 Associate Professor Holly Teagle, University of Auckland, New Zealand
 Professor Paul Van De Heyning, Antwerp University Hospital, University of Antwerp, Edgem, Belgium
 Professor Christophe Vincent, Centre Hospitalier Regional, Universitaire de Lille, France
 Professor Hao Wu, 9th People's Hospital, Jiao Tong University School of Medicine, Shanghai, China
 Professor Tatsuya Yamasoba, The University of Tokyo Hospital, Tokyo, Japan
 Dr Terry Zwolan, University of Michigan, Ann Arbor, MI, USA

*Note, these panel members shared a voting role so are counted as only one voting member

Consumer and Professional Advocacy Committee (CAPAC)

MS BARBARA KELLEY (CO-CHAIR)
EXECUTIVE DIRECTOR OF HEARING LOSS ASSOCIATION OF AMERICA (HLAA)

DR HARALD SEIDLER (CO-CHAIR)
CI USER, REPRESENTATIVE OF THE INTERNATIONAL FEDERATION OF HARD OF HEARING PEOPLE AND IMMEDIATE PAST PRESIDENT OF THE GERMAN ASSOCIATION OF THE HARD OF HEARING (1996- 2019)

DR LEO DE RAEVE
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS (EURO-CIU)

PROFESSOR BERNARD FRAYSSE
INTERNATIONAL FEDERATION OF OTORHINOLARYNGOLOGICAL SOCIETIES (IFOS)

MS DARJA PAJK
EUROPEAN FEDERATION OF HARD OF HEARING PEOPLE (EFHOH) AND CI USER

MS DONNA SORKIN
AMERICAN COCHLEAR IMPLANT (ACI) ALLIANCE AND CI USER



Result: 7 categories, 20 statements

1. Level of awareness of CIs
2. Best practice clinical pathway for diagnosis
3. Best practice guidelines for surgery
4. Clinical effectiveness of CIs
5. Factors associated with post-implantation outcomes
6. The relationship between hearing loss and depression, cognition, and dementia
7. Cost implications of CIs



Geneva meeting (Dec 2019) of CAPAC + other important organisations: Advocacy is key to real-world acceptance

- CAPAC members were given the **opportunity to comment on consensus statements** and make suggestions at each round, but did not take part in the voting of the Delphi process
- **CAPAC stressed** that knowledge alone is not enough to achieve acceptance and adoption of the consensus statements: **promotion and advocacy** will be important
- The **perspectives of CI-users** must be taken into account
- The CAPAC plus other important organizations representing CI-Users and CI professionals: **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**. Why?
- 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.



Option for EURO-CIU MEMBERS



Standard of Care

Main resources available in local language



- **Translate** the Word version, send it to EURO-CIU & CAPAC will prepare the one page with graphics and get it back to you.
- EURO-CIU Logo included and **option to include your own association logo**



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5.





**CI International Community of
Action (CIICA)**

**Sue Archbold
Brian Lamb**

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Consultation on CI Advocacy after the Geneva meeting about the International Guidelines for CI



We asked people about the barriers to CI, the role of advocacy work in increasing access to CI

- 31 Interviews: from 21 countries; 17 users, 8 professionals, 6 industry
- Survey sent out to global stakeholders : 28 countries

Huge support for this initiative by user and family groups, professionals and industry

The world has changed with impact of COVID19 : this initiative is even more important

Strong agreement of the barriers to access to CI: :

- Lack of awareness of HL and CI
- Lack of referrals for CI
- Insufficient funding: budgets reduced with the challenges of COVID19

Even greater need for CI advocacy work – the problem is HUGE.....

Only 5% of adults in developed countries with access to CI..... And the rest?



Strong support for advocacy work:



- Increased grass roots action in time of societal change
- Diverse: languages, cultures, health and education care systems
- Messages from users and families are powerful
- Decision makers listen to user/family groups,
- Users and families really know what is needed.... Which might not be what is being provided...
- They want an equal seat at the table.... Or the screen
- *“A happy consumer tips the decision making....”*
- *“only chance of success is the advocacy voice.....”*
- *52 examples of successful advocacy work globally were reported*



Strong desire for action and new collaborative ways of working together...



Some challenges:

- Time: often voluntary, with full time work commitments, and managing hearing care and technology
- Limited resources –both time and money
- “the biggest enemy is time.....”
- Diverse needs – different systems
- Too many organisations – need to have a common voice and message

Suggestions for new ways of working together which valued all the work by organisations currently being done

- Flexible and fast moving.....
- More possible today with the latest technologies.... Like today!

“lots of work done by separate groups but it was the coming together with one voice for success....”



So we listened and we propose ... CI International Community of Action



Why a Community of Action? People didn't want a new organisation, with the burden of new bureaucracy. They wanted a voluntary community – with shared goals, to bring about change, but consisting of recognisable and diverse but valued groups.

The vision of CIICA is a world in which awareness of the benefits of CI are well known to those with hearing loss, their families, professionals in the field of hearing loss, the general public and public health decision makers. A world where access to CI and lifelong support is available where appropriate.

Goal of CIICA

To increase the number of people globally who have access to cochlear implants and lifelong aftercare **by supporting CI advocates with the tools they need to achieve change.**

Independent, Collaborative, Inclusive, Empowering, Promotes Trust, Diverse, Accessible, User/family led



A trusted space to share and collaborate. A digital platform for CIICA



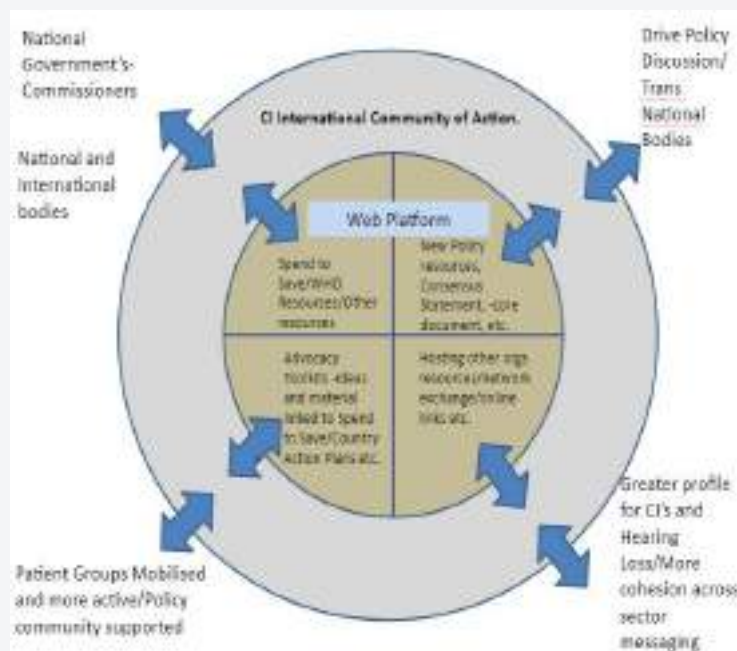
Fundamental is a digital platform which will act as the centre for this CI Community of Action

- Bringing together diverse advocacy organisations worldwide
- Providing shared resources, activities and research
- Providing opportunities for research
- Provide the global voice and influence for CI advocacy
- Increasing this voice and influence
- Providing the tools for change for advocacy

NOT a conventional website, but the hub of CI action



An ACTIVE digital platform....



Our proposal for CIICA



Impact

Improved access globally to cochlear implantation, rehabilitation, life-long technical support including processor upgrades and aftercare driven by CI user and family advocacy initiatives.

Gandhi- *Be the change you want to see in the world....*

Archbold – *but it may take time...*



Such a voluntary community can be active soon, but can evolve over time.....

Working together globally, in line with the goals of WHO and its advocacy work and the launch of the World Report on Hearing in 2021

The work of EURO-CIU is an example to all.

Please get in touch if you want to know more. sue.archbold@btinternet.com



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WHO – World Hearing Forum (WHF) – Members certification

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Member of

WORLD

HEARING

FORUM

(World Health Organization)



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- We represent **33** associations from **23** countries from Continental Europe
- We want more of you in

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WHY?



- Alliance with other members working on similar projects and ideas
- Support of WHO can help your own country work



World Health Organization



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WHY?



Alliance | Advocacy | Action

- Advocacy Works better with everybody pushing on the same direction
- Advocacy on Hearing in general to improve Screenings, Hearing aids and CI and Breaking Communication Barriers



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HOW?



Alliance | Advocacy | Action

4 Task forces:

- World Hearing Report
- Champions for Hearing
- World Hearing Day
- Make Listening Safe

Webinars in english with captioning to learn how to help and contribute



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- **World Hearing Report**
done by WHO. WHF helps to spread the message to governments around the world



*World Report
on Hearing*



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**If you know
somebody,
let us know!**

- Looking for famous people to spread the message
- Looking for hearing loss related persons who are heroes

f t d

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Champions



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- You can join WHF activities or organize in your country all year long or just for

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World Hearing Day



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World Hearing Day

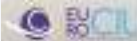


DON'T LET HEARING LOSS LIMIT YOU



Hearing for life

WorldHearingDay, 3rd March 2020



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World Hearing Day



Alliance | Advocacy | Action



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World Hearing Day
3 March 2021



HEARING CARE FOR ALL
SCREEN • REHABILITATE • COMMUNICATE



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KEY MESSAGES **Policy makers**

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- The number of people living with unaddressed hearing loss and ear diseases is unacceptable.
- Timely action is needed to prevent and address hearing loss across the life course.
- Investing in cost effective interventions will benefit people with hearing loss and bring financial gains to the society.
- **Governments must act to integrate person-centered ear and hearing care within national health plans for universal health coverage.**



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KEY MESSAGES **General public**

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- Good hearing and communication are important at all stages of life
- Hearing loss (and related ear diseases) can be avoided through preventative actions such as: protection against loud sounds; good ear care practices and immunization.
- Hearing loss (and related ear diseases) can be addressed when it is identified in a timely manner and appropriate care sought
- People at risk of hearing loss should check their hearing regularly
- People having hearing loss (or related ear diseases) should seek care from a health care provider



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Key graphics is available in the six UN official languages (Arabic, Chinese, English, French, Spanish and Russian). Thanks to the support of members of the World Hearing Forum, it is also available in in Bengali, Georgian, German, Hindi, Italian, Indonesian, Javanese, Korean, Portuguese, Swahili, Turkish, Urdu, and Vietnamese.

EURO-CIU has the editable material for you to translate to your own language if you so desire

Only condition, is to change WHO logo for EURO-CIU and your own logo.

The "egg" can stay 😊

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World Hearing Forum



- **Last day to submit your application to join the World Hearing Forum in 2020 is Friday, 30th October**
- **They ask for an anual report of your activities following the WHF objectives**

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World Hearing Forum (WHF) Make Listening Safe

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Fourchaine Slide Show - Make Listening Safe WHF Workgroup Action Plan 18-05-2020.pptx - PowerPoint

Create a world where nobody's hearing is put in danger due to unsafe listening

Make Listening Safe

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Safe Listening Group
**EURO-CIU is on
Social Media
and Safe
Listening
Practices group**



**Safe Listening Practices, especial
for Young groups**
**WHO-ITU Global standard for safe
listening devices and systems, like
phones – Iphone already working**
**Develop a regulatory framework for
control of exposure to sound in
entertainment venues – Belgium
example**

**Communication campaign for safe
listening, social media, podcasts,
etc.**

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Safe Listening Group
**EURO-CIU is on
Social Media
and Safe
Listening
Practices group**



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– **Young Safe Listening Ambassadors program**

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8.



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**European Disability Forum
EDF**



EU Disability Forum
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EDF - AGM 2020

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EDF's planned **activities for 2021**, based on the 4-year-strategic plan from 2018:

- a new Disability Rights Agenda for the next 10 years should be published 2021
- Study Persons with disabilities and the EU's response to the COVID-19 crisis
- Promote the widening of the pilot project of the Disability card to remaining EU member States
- Better implementation and improved Passengers' Rights legislation
- Promote the increased collection and use of disability related statistics at EU and national level in line with CRPD



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Resolution on Covid- 19 and the rights with disabilities

- 15% of the total population are persons with disabilities; pandemic are having effect on persons with disabilities and their families. All EU Member States have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD)
- Every person has right to immediate information on the pandemic, this includes information provided through public websites and relay services with **real time text services**
- To an absolute minimum, the following should be included both **live captioning** and sign interpretation must be provided
- EU have committed to the 2030 agenda for Sustainable development and its 17 development goals, which includes **quality education** (SDG 4)
- EDF is recognising that children and students with disabilities have more difficulty accessing **quality inclusive education** and exclusion may worsen during the pandemic

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Sari Hirvonen-Skarbö

The Web Accessibility Directive came fully into force 23.09.2020

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- All public-sector websites across the EU must be accessible for persons with disabilities.
- There is no excuse for public websites and applications not to be accessible for persons with disabilities.
- all videos published on the Website must be have subtitles. All online videos must have subtitles or have readable text available.
- Covid -19 information and live broadcastings should be with subtitles or mobile information with RRT



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Sari Hirvonen-Skarbö

Survey about the Web Accessibility Directive in Europe

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- all public sector websites must comply with the requirements of this legislation. Study if this is the case and country has actually taken full advantage of the Web Accessibility Directive.
- Survey is intended for persons with disabilities
- EDF will prepare a public report to be presented to the relevant EU institutions and distributed broadly to put pressure on the public sector at national level to make their digital services more inclusive to persons with disabilities

www.surveymonkey.com/r/BMRJHN6



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Webinars by EDF

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Poverty and Social exclusion of Persons with Disabilities

- Increased risk of poverty and social exclusion for persons with disabilities in percentage
- Only 50.8% of persons with disabilities are in employment, compared to 74.8% for persons without disabilities.

Advocating for strong national adoption of the European Accessibility Act

30 December

Conference on Covid 19 and Disability – building a better future

30 October



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Thank you!



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MOSAICS

Robert Mandara

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MOSAICS

- ▶ A European Industrial Doctorate project funded by the European Union's Horizon 2020 framework programme for research and innovation.
- ▶ It will train future experts and leaders in auditory implants to achieve minimized outcome spread and maximized participation in society.
- ▶ Program led by Cochlear Ltd & the Radboud Medical Centre in the Netherlands. EURO-CIU is a supporting partner.




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Four early stage researchers (ESRs)



Ignacio Calderon de Palma, Objective measures

Investigate the "body functions" by evaluating the neuronal activity following sound and speech stimuli at the level of the cochlea, brain stem and cortex, using biophysics methods.



Loes Beckers, Cognition

Address the cognition (brain) effects on process-related outcome measures in relation to CI performance.



Nikki Tromp, Societal benefit

Evaluate the societal benefits of CI-specific rehabilitation programmes and recipients' social support.



Enrico Migliorini, Fitting Engineering

Adopt an engineering approach and the aid of AI to explore "environmental factors", obtaining insight into the fitting issues related to outcome spread.



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Fresher's week online due to Covid-19

Leo De Raeve, Sue Archbold & I gave induction training.

Katka Nova may be involved face-to-face later.



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MOSAICS



- ▶ The ESRs are expected to present their findings in a future EURO-CIU Symposium.

- ▶ For more information:

<http://www.mosaics-eid.eu/>

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Hearing Health Forum EU Henri-Francois Baiverlin

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f t d

Hearing Health Forum EU

Forum members :


MEP Alex Agius-Saliba, Chairman of the Hearing Health Forum EU, representing the politics

Patrick D'Haese (Med-EL), representing the European industry

Prof. Paul van den Heyning (University Antwerp), surgeon and academic

Henri-François Baiverlin (Euro-CIU), users and parents

Emma Cracknell (Vice-President FleishmanHillard),



Priorities :



- *MEP Alex Agius Saliba* MEP Agius-Saliba to talk Forum members through healthcare and disability priorities in the European Parliament
- Our key priorities for the Forum and how we might achieve that in current political landscape



activities to date :



*3 meetings,
Preparation of key messaging document and Q&A,
Explanation about Parliamentary priorities,
Website development*



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**PHOTO TIME, Please turn on
your cameras and we will
make the group photo**

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**ONGOING
projects**

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COVID introduction

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COVID introduction




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-Huge impact of COVID-19 on Cochlear Implantation: medical appointments, selection, operation, fitting, rehabilitation, upgrade devices,... (see survey)

-Huge impact on communication (masks; online meetings, webinars, ...), **education, social life and mental health.** (see impact of masks, hospitalization documents, accessible (online) education,...)

-Does Covid-19 cause hearing loss????



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COVID introduction



f t y

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Is there good quality evidence?



- Rapid systematic review
- Diagnosis of coronavirus e.g., SARS, MERS, SARS-CoV-2
- Change in hearing, tinnitus, hyperacusis, vertigo

FREE ACCESS: doi.org/10.1080/14992027.2020.1776406

Audio-vestibular symptoms



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COVID introduction



f t y

76

Implications for hearing services?



- Serial hospitalized cases (n = 121), March-April 2020
- SARS-CoV-2 confirmed with swab using rRT-PCR test
- Reviewed 8 weeks after discharge, as per usual care
- Detailed history, including hearing and tinnitus

FREE ACCESS: doi.org/10.1080/14992027.2020.1776406

16 (13.2%) reported a change in hearing or tinnitus

- 8 report deterioration in hearing (4 pre-existing HL)
- 8 reported tinnitus (3 pre-existing HL)

Summary so far

- Involvement of the audio-vestibular system unclear
- Lacking high-quality studies investigating:
 - Acute and temporary effects
 - Long-term risks
- Urgently need a carefully conducted clinical and diagnostic study to:
 - Understand long-term manifestations
 - Provide timely estimate of disease burden

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PRODUCERS TIME

How is your brand / firm approaching the pandemic, and what tools have you implemented to attend to your users?



f t y 79





15 minutes break
CI Voices and
Videos show

@eurociu



f t y 80



11.C

COVID

FROM OUR MEMBERS
TO EURO-CIU

#EUROCIU20



f t y 81




COVID

Keeping CI users connected in hospital

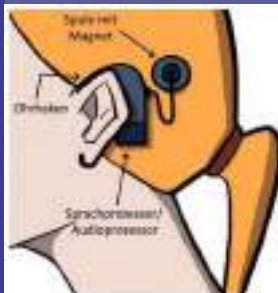
Reinhard.Zille@BayCIV.de





**Bayerischer Cochlea
Implantat Verband e.V.**


Motivation

- ▶ imagine you have to go to hospital
- ▶ you must be quarantined
- ▶ you are a CI user
- ▶ AND NOBODY KNOWS ABOUT CI's
- ▶ **Simply visit**
- ▶ <https://www.bayciv.de/news/1221>
- ▶ **And download the template for the manufacturer you are using**



**Informationen
für den
Notfall**






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Hospitalisation Documents

- We engaged EURO-CIU to produce English language versions for all of the most common processors. These can be downloaded from EURO-CIU's website
- The member associations have translated and distributed the documents into other languages including Italian, Spanish, Finnish and Georgian.
- While the forms were originally created for use in the pandemic, they can be useful in the future whenever CI users are hospitalized, both at home and when they are abroad for work or holidays.**

• <http://eurociu.eu/emergency-document-for-use-if-cochlear-implant-users-become-hospitalised-->





Bayerischer Cochlea
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New Stuff available

Check out our new brochure for the elderly:
Cochlear implant (CI) users in hospitals, nursing homes and similar institutions

• <https://www.bayciv.de/news/informationsbroschuere-senioren>

MAYBE IT's WORTH TO BE TRANSLATED TOO





f t y 85

- **Thank You**
- **And keep safe**

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f t y 86

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COVID

**Accessible
Education**

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#CochlearImplant

COVID

ACCESSIBLE EDUCATION

- **ONLINE EDUCATION must be accessible as well**
- **Have you had any problems?**
- **EDF wants to know your problems - Collaboration to do a position paper otherwise we will be biased with only showing comments from a couple of countries**

f t y 87



f t y 88



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COVID

Communication
masks

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f t d 90

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COVID
Communication Masks



- **Working with EDF - European Parliament standardization clear masks**
- **Welcoming good practices about masks from countries**



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COVID
Communication Masks



Spain has done a campaign
raising awareness
20,000 masks 20,000 smiles
WORKING ON CERTIFICATION
aice@implantecoclear.org



f t y 91





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COVID

CI SURVEY

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f t d 94

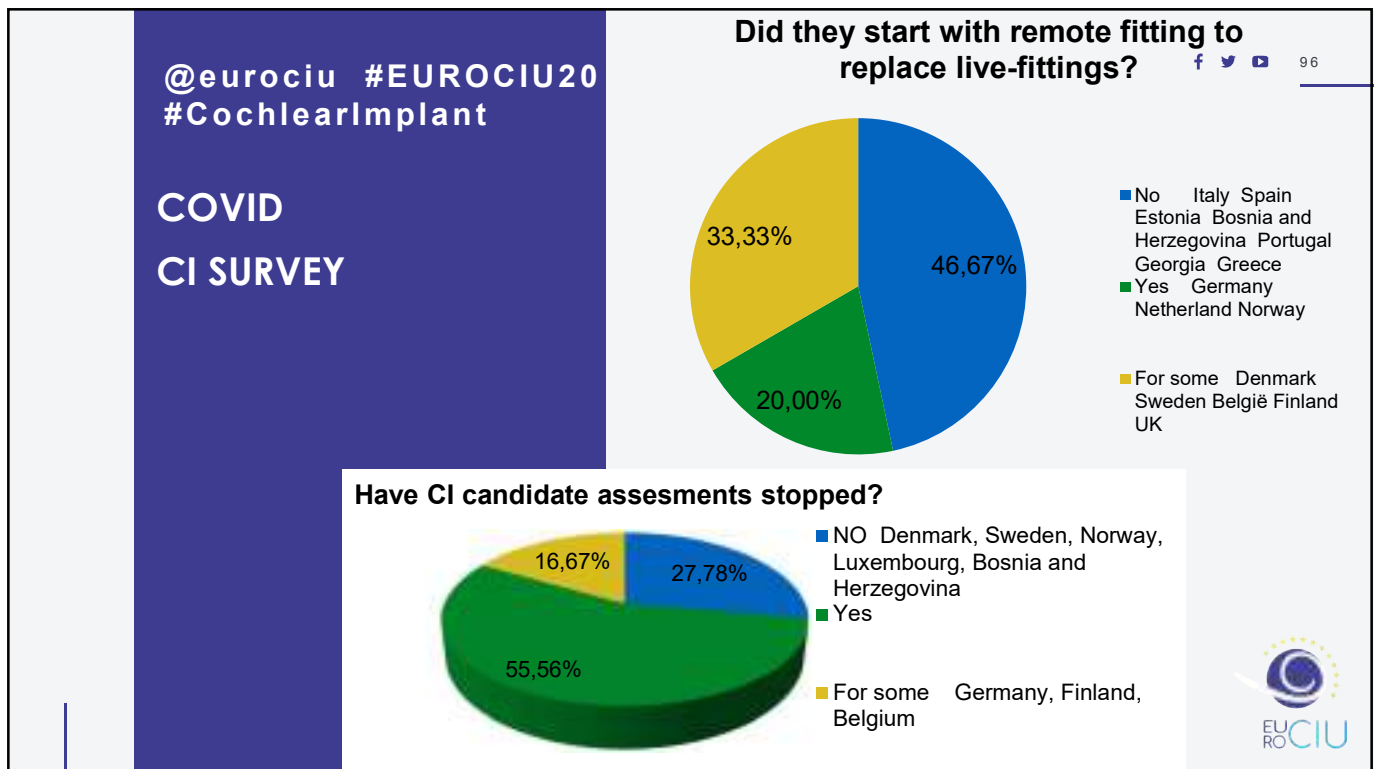
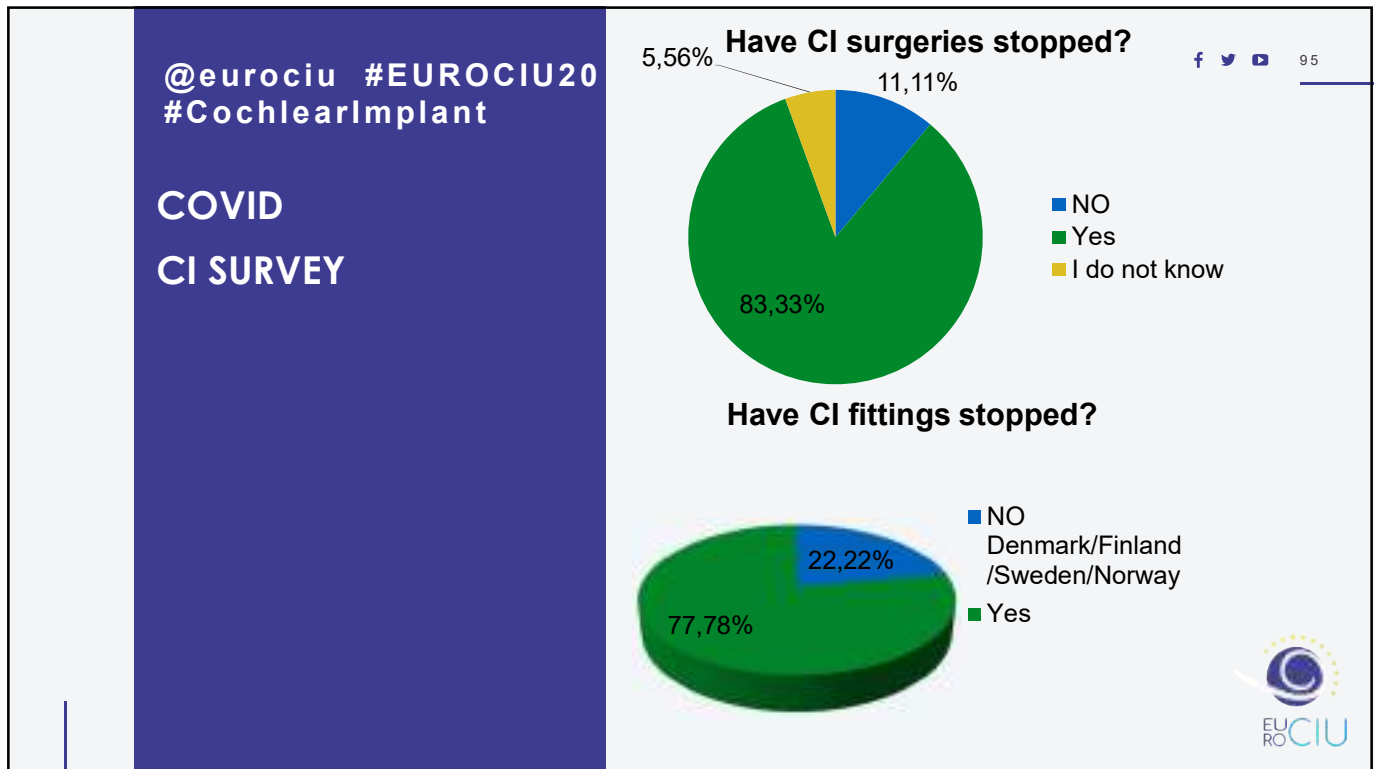
[@eurociu](https://twitter.com/eurociu) [#EUROCIU20](https://twitter.com/eurociu)
[#CochlearImplant](https://twitter.com/eurociu)

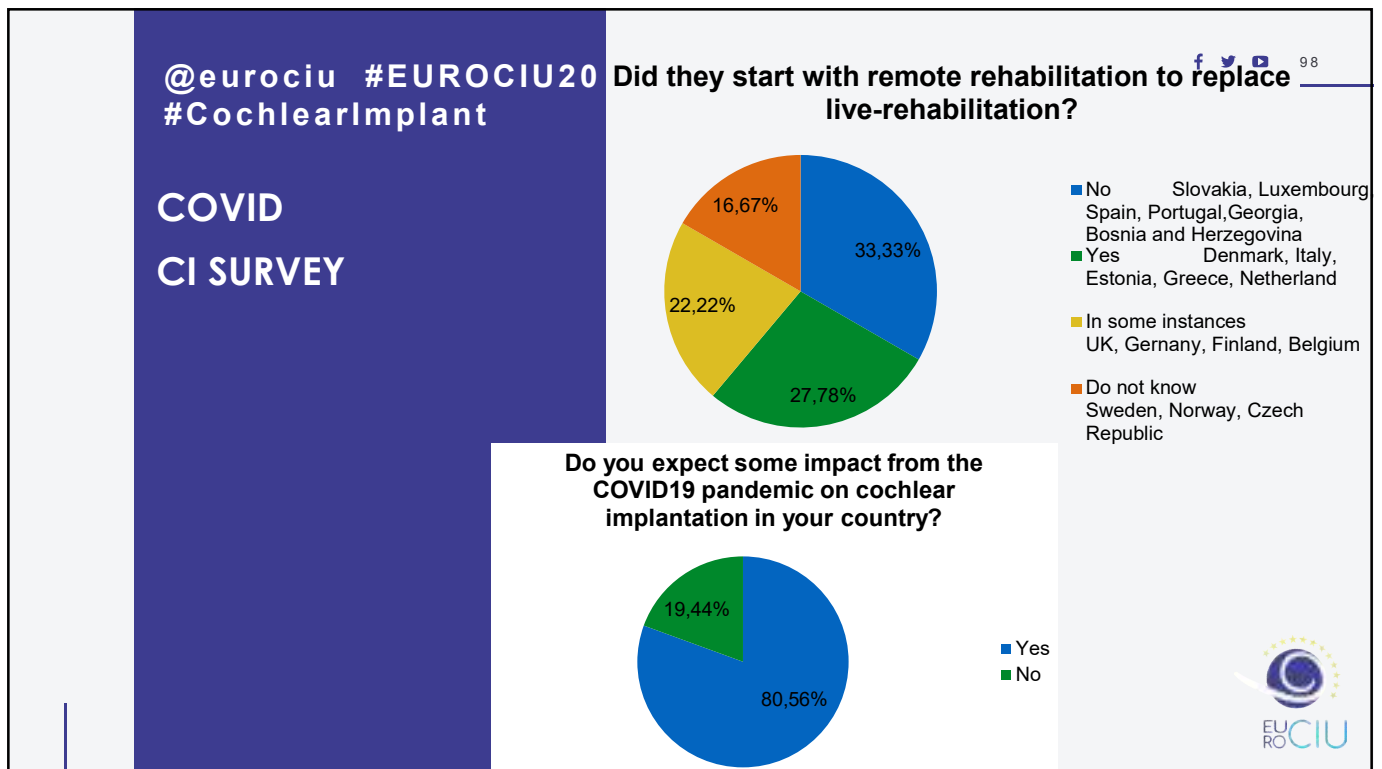
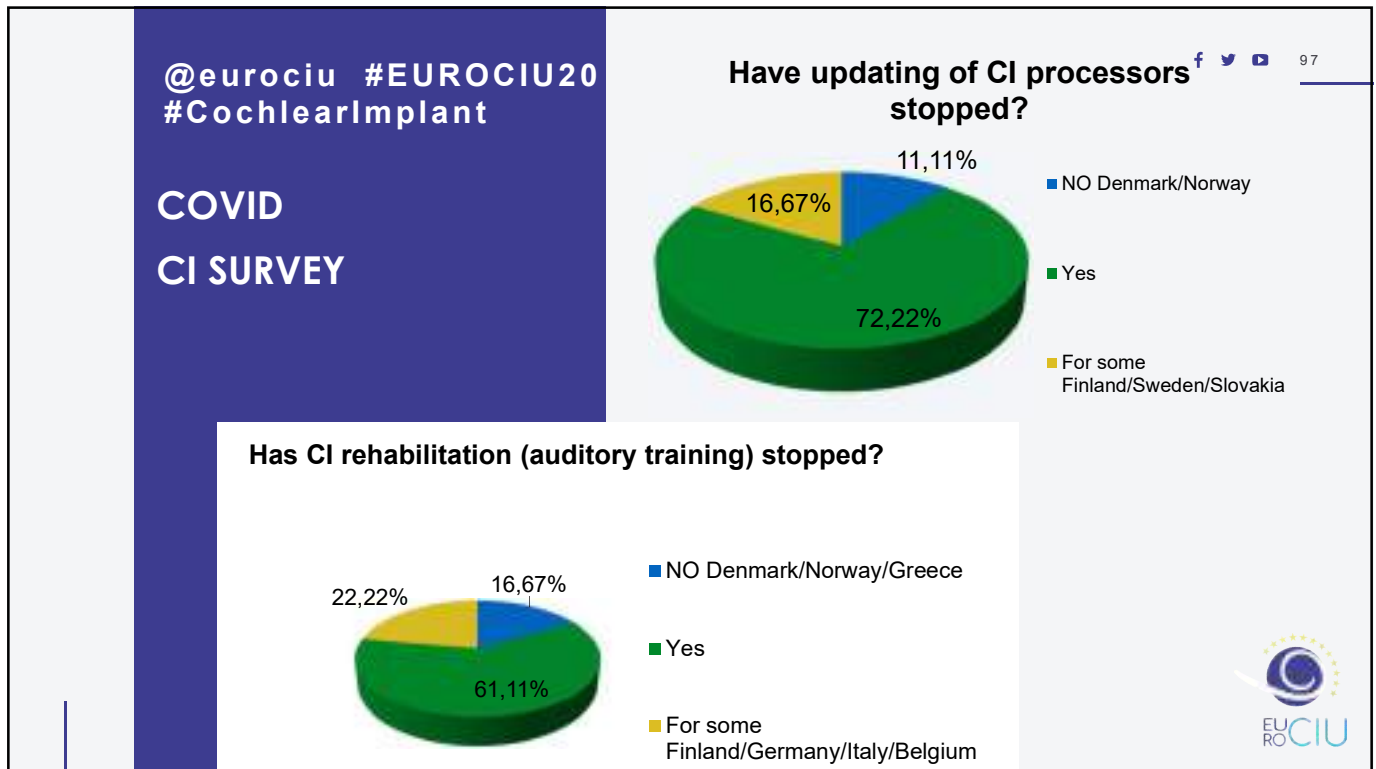
COVID
CI SURVEY


This survey has been carried out on the situation of Cochlear Implantation in Europe due to COVID19 in the 3rd week of April.


We have obtained 20 responses representing 18 countries. From Finland and Germany, 2 representatives responded.















<p>@eurociu #EUROCIU20 #CochlearImplant</p> <p>COVID CI SURVEY</p>	<p>f t d 99</p>
	<p>Cochlear implantation operations have been stopped in all countries, they have not been considered urgent. Cases of meningitis have entered the concept of urgent health, such as cases of stroke or oncological treatments and have been treated as a priority, in each country, when hospital conditions have allowed it.</p> 

<p>@eurociu #EUROCIU20 #CochlearImplant</p> <p>COVID CI SURVEY</p>	<p>f t d 10 0</p>
	<p>CONCLUSIONS:</p> <ul style="list-style-type: none"> - At the time of the survey, in most countries, there was insufficient information. - The COVID19 pandemic may provide a push towards remote programming of cochlear implant processors. - There is concern that economic resources will be challenged in the future and result in cuts in cochlear implantation programs. 

<p>@eurociu #EUROCIU20 #CochlearImplant</p> <p>COVID CI SURVEY</p>	<div style="text-align: right;">    10 1 </div> <p>CONCLUSIONS:</p> <ul style="list-style-type: none"> - EUROCIU can collaborate by facilitating the sharing of information and different situations, between different countries. We must have public positions on the issues that impact on cochlear implantation, and act politically in front of the European organizations. We should publish reports that serve as support to organizations to make their positions clear to the governments of their countries. - WE WANT TO REPEAT THE SURVEY IN A FEW MONTHS, WE EXPECT YOUR COLLABORATION <div style="text-align: right;">  </div>
--	---

<p>@eurociu #EUROCIU20 #CochlearImplant</p> <p>COVID CI SURVEY</p>	<div style="text-align: right;">    10 2 </div> <ul style="list-style-type: none"> - Initial Survey - done - Repetition of the survey? - End of 2020 - End of the Pandemic 2021 - To see the evolution <div style="text-align: right;">  </div>
--	--





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f t y 10
 3


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**Euro-CIU Survey on
CI-data of 2010 and 2016**


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f t y 10
 4

12.

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#EUROCIU 20

f t y

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Euro-CIU Survey on CI-data of 2010 and 2016

-Data of the EURO-CIU survey of 2010 and 2016 were **published in Cochlear Implant International in May, 2020**

-We would like **to measure if there is an impact of COVID-19**

-So we would like **to collect now the data of 2017 and 2018**
and **next year the data from 2019 and 2020**



Cochlear Implants International
An Interdisciplinary Journal

ISSN: 0195-3014 (Online) Journal Homepage: <https://www.landforonline.com/doi/10.1002/ci.120>

Prevalence of cochlear implants in Europe: trend between 2010 and 2016

Leo De Raeye, Sue Archbold, Monika Lehnhardt-Gorlany & Tricia Kemp

To cite this article: Leo De Raeye, Sue Archbold, Monika Lehnhardt-Gorlany & Tricia Kemp (2020) Prevalence of cochlear implants in Europe: trend between 2010 and 2016, Cochlear Implants International, 21:5, 275-280, DOI: [10.1080/14620109.2020.1771829](https://doi.org/10.1080/14620109.2020.1771829)

To link to this article: <https://doi.org/10.1080/14620109.2020.1771829>



f t y

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[f](#) [t](#) [v](#)
10



25th Anniversary Postponed

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[#CochlearImplant](#)

25 anniversary



- **Postponed to 2021**
- **Inside the European Parliament event**
- **Visit the parliament**
- **Related meetings with country politicians**
- **Plus a social event**
- **2 months in advance we will have confirmation**

[f](#) [t](#) [v](#)
10




f t d 10
9



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f t d 11
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14.

**Germany 2021
canceled**

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#CochlearImplant

EURO-CIU 2022 Symposium



- Germany will not organize in 2021 or 2022
- Looking for new candidatures
- Deadline for candidatures December 2020
- THE BOARD will decide between candidates in case there are more than one

f t d 11



15.



European Friendship Week (EFW)

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f t d 11



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EFW July 2019

- ▶ EFW, a summer camp for European CI users, sponsored by The Ear Foundation & EURO-CIU, rated "Outstanding" by UK Ofsted.
- ▶ 48 youngsters (11 – 16 year olds).
- ▶ I volunteered at EFW in 2018 and 2019.
- ▶ Participants make international friends, enjoy peer support, learn team-working & problem-solving skills and practice using English.
- ▶ Participants may very well be inspired to become future CI advocates and active in EURO-CIU.


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3


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EFW 2020...

- ▶ Didn't happen.
- ▶ The Ear Foundation charity closed down at the start of the year.
- ▶ A new charity, Hear Together, was created by former leaders of The Ear Foundation.
- ▶ EFW was scheduled for 2020 but was cancelled due to Covid-19.

 11
4

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EFW 2021...

- ▶ The leaders of Hear Together have indicated that they would like to cooperate with EURO-CIU as before. **Open to other candidatures.**
- ▶ Due to Covid-19, nobody knows if EFW will happen again in 2021.
- ▶ I hope that it does because it is of huge benefit to young CI users and the future of EURO-CIU.

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f t y 11
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16.



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CI Day & Slogan

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f t y 11
8


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#CochlearImplant

**2021 Cochlear
Implant Day**

**I want to hear: can you
hear me? #CIDay**



I want to hear.
Can you hear me?

<http://eurociu.eu>



I want to hear.

Can you hear me?



<http://eurociu.eu>



Look after her, do not let her miss her hearing. She has a long life ahead.



12

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17.



f t d 12

Vice President vacancy

Elections 2021 for secretary and vicepresident

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18.



12

3



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New Project: CI and cognitive decline and dementia

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Sue Archbold
Brian Lamb



A new document: Last year in Wroclow:



We launched with EUROCIU the briefing report :

Hearing Care, cognitive decline and dementia: A public health challenge or an opportunity for health ageing?

It highlights the risk factors for dementia, including hearing loss as the most significant.



It provides the evidence base for



- Links between hearing loss and cognition
- Risk factors for dementia
- Can addressing hearing loss help maintain cognitive functioning?
- The importance of better hearing with the latest technology
- The costs of not addressing hearing loss, dementia and cognitive decline
- References – growing regularly over this year
- For example the latest **Livingston, G. et al., Dementia prevention, intervention, and care: 2020 report of the Lancet Commission**, updating the 2017 report still has addressing Hearing loss the largest single modifiable risk factor for dementia.
- It has been used in the last year by audiologists world wide to influence older people to take action on their hearing loss.



We know that with our ageing population the issue is growing globally....



Over 60% of adults living with dementia will also have hearing impairment (Nirmalasari et al 2017) and over 90% of adults living with dementia in aged care will have HI (Hopper et al, 2016)

50 million people over 65 have been diagnosed with dementia and this is expected to triple by 2050.

The costs of caring for those with dementia was \$820 billion in 2015.

Hearing loss is believed to directly increase the risk of cognitive decline and dementia through the effects of hearing loss on the brain and social isolation. (Lin, Albert, 2014)

Investments in early intervention and early provision of hearing aids and implants will not only improve quality of life for older people, but will also save health systems additional medical and social costs in the future.

The growing message is Sort out your hearing! See the AICE Twitter feed



We recommended:



- **Actions for governments**
 - National Action Plans on Hearing Loss
 - Public Health Campaigns
- **National Screening Programmes for Hearing Loss**
 - National screening programmes for adults, improving early access to hearing aids and implants
 - Sensitive to the association with dementia and cognitive decline
 - Targeted screening in care homes, in homes
- **Training**
 - Training in identifying and managing hearing loss for those with dementia
 - Interprofessional teams involved with the management of dementia and cognitive decline
 - Supporting personal advocacy in management of hearing loss for those living with dementia



And now... what about the role of cochlear implants: a new EURO-CIU paper



- The Board of EURO-CIU have asked us to undertake another short briefing paper focussed on cochlear implantation and dementia and cognitive decline to be available for you.
- The specific evidence in this area is less clear, but we are in the process of looking at it to be able to provide the up to date evidence about managing hearing loss with CI and cognitive decline and dementia. It will be short so that it can be translated and used like the Spend2Save format.

With thanks to Cochlear for supporting the dementia briefing paper; it is the work of authors. Huge thanks to a number of reviewers who informed our understanding.

MEMBERS WILL BE ABLE TO USE IT AS WELL TRANSLATED IN THEIR OWN LANGUAGES









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19.

**Bullying and
Cyberbullying
in CI students**
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#CochlearImplant**

Bullying and Cyberbullying among Students with Cochlear Implants

**OXFORD
Journal of Deaf Studies & Deaf Education**



The screenshot shows the article title, authors (Sandra Inghile, Habbat Foody, Habbat Fichtel, Lila Zariwala, Barbara Kall), the journal name, and the publication date (30 September 2020). It also includes an abstract snippet and social media sharing options.




13



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EURO-CIU work

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13



20.



EURO-CIU logo and link

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13
3

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As members, associations are obliged to include the EURO-CIU link and logo on their websites.

<http://eurociu.eu/>

We are proud members of






13
4

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 #HearingCare
 #CochlearImplant

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f t y 13
5

Why?

- ▶ Visibility & awareness: the more visible we are, the more we will be heard.
- ▶ EURO-CIU's website shows the associations' logos and links. This should be reciprocal.
- ▶ EURO-CIU represents 220000 CI users.
- ▶ How many members of your association have heard of EURO-CIU? Showing your affiliation will make your members aware of us.
- ▶ Your members are the future of EURO-CIU.

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#CochlearImplant



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Today, although we have sent many reminders, only two associations display both the correct logo and link.

Many others feature the old logo and/or an old or broken link.

Please fix this after the GA. Contact me if you need assistance.



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**Please also include the logo
and link in articles whenever
EURO-CIU is mentioned.**



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f t y 13
9

Apps & resources to our website

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Resources to website

- ▶ Books
- ▶ Research papers
- ▶ Apps



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14

1

- Please tell us about useful resources.
- Name, author(s), ISBN
- Initially in English.
- This is not a library.

C.I. REFERENCES

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14

2



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22.

14
3

CI Voices

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#CochlearImplant

WANTED!
CI user videos

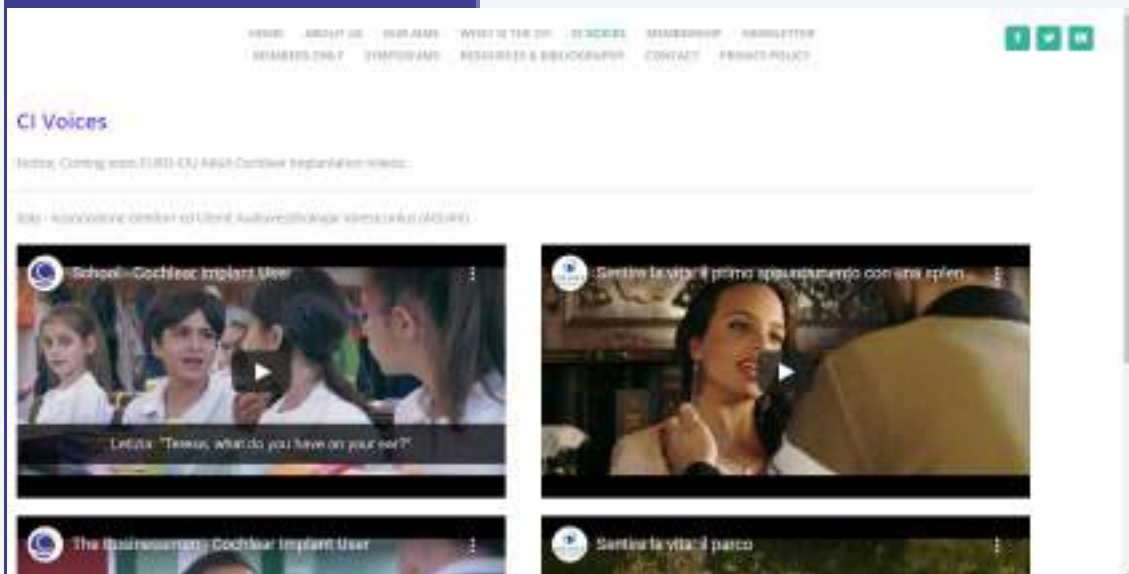
14
4

- We need videos of CI users talking about their implants.
- Videos can raise awareness of CI users and to motivate policy makers.
- Please send us videos with permission to use and, if possible, captions.
- <https://www.youtube.com/watch?v=zTKOkywkeog&list=PLyKiEZvQ5CrJfhXJOlm682ZFhkiT6zXXu&index=3>

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#CochlearImplant

f t y 14
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- CI VOICES



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6

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f t y 14
7



EURO-CIU Website

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#CochlearImplant

- Eurociu.eu

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8

WEB

The screenshot displays the Eurociu.eu website with the following content:


- Header:** "Download June 15, 2020 by Ylmarinen EUROCIU"
- Left Sidebar:**
 - EUROCIU logo
 - ANNUAL REPORT 2019
 - Download Annual Report 2019
 - Download June 15, 2020 by Ylmarinen EUROCIU
 - Spend To Save - 2nd Edition!
- Main Content Area:**
 - Download complete document in PDF format
 - Medical: (coming soon) EUROCIU Annual Cochlear Implantation survey 2019
 - EUROCIU Survey Cochlear Implantation situation COVID19
 - May 15, 2020 by Ylmarinen EUROCIU
 - EUROCIU Survey Cochlear Implantation situation COVID19 PDF
 - Have CI surgeries stopped?
 - Did they start with remote fitting to replace live fittings?
- Right Sidebar:**
 - It is important that there are more transparent results available. @eurociu, @Audiology @Eureplanning @Aural_Toness
 - Facebook: Eurocki
 - Youtube: More videos on the EUROCIU channel

**@eurociu #EUROCIU20
#CochlearImplant**

WEB

f t y 14
9

- Include on the website of each Association the EURO-CIU logo and its link.
- Send news to webmaster@eurociu.eu who want them to appear on the EURO-CIU website. If possible with a headline and then the news.
- Remember that the private zone only needs the password that is common for everyone.







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24.



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f t d

15

1

EURO-CIU Newsletter

@eurociu



Newsletter 2019

- ▶ 5 issues – quarterly plus Special General Assembly edition
- ▶ Number of readers varies from issue to issue – between 1,850 and 2,300
- ▶ Average of 2,120 readers per issue in 2019
- ▶ Newsletter software sends out each edition milliseconds apart to individual e-mail addresses, so it's not picked up as SPAM!



f t d

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2





EURO-CIU Newsletter 2019

- Each issue has an average of 30 articles – from EURO-CIU itself, from our members, from partner organisations and from the manufacturers
- 13 of our member organisations provided articles last year – it's good to know what is happening across Europe – so more articles (with photos) would be warmly welcomed.
- We are grateful that Advanced Bionics, Cochlear, MED-EL and Oticon Medical provide articles for each issue, to bring us up to date.



EURO-CIU Newsletter

- Over last year, 61 countries from all over the world received our newsletter – from Albania to Vietnam (alphabetically) – but from Europe to the Far East to the Americas, Africa and Australasia.





EURO-CIU Newsletter

Some points to remember: Newsletter is read by:

1. Your members – and remember that you can forward it to them, or you can tell me their e-mail addresses, and I'll send it direct to them
2. Professionals, and people with cochlear implants worldwide
3. Cochlear Implant manufacturers, including their CEOs
4. Some well-known and well-respected individuals (eg Prof Graeme Clark)
5. Members of Parliament and Members of the European Parliament
6. Organisations such as WHO

So, please let me have your articles!!



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25.


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Finances

Henri-Francois Baiverlin

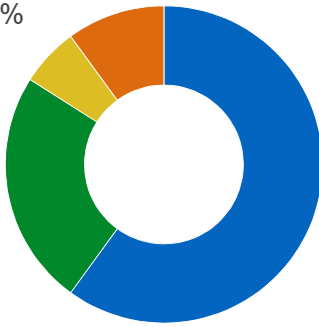
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Financial situation 2019


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Our revenues in % for 16 years

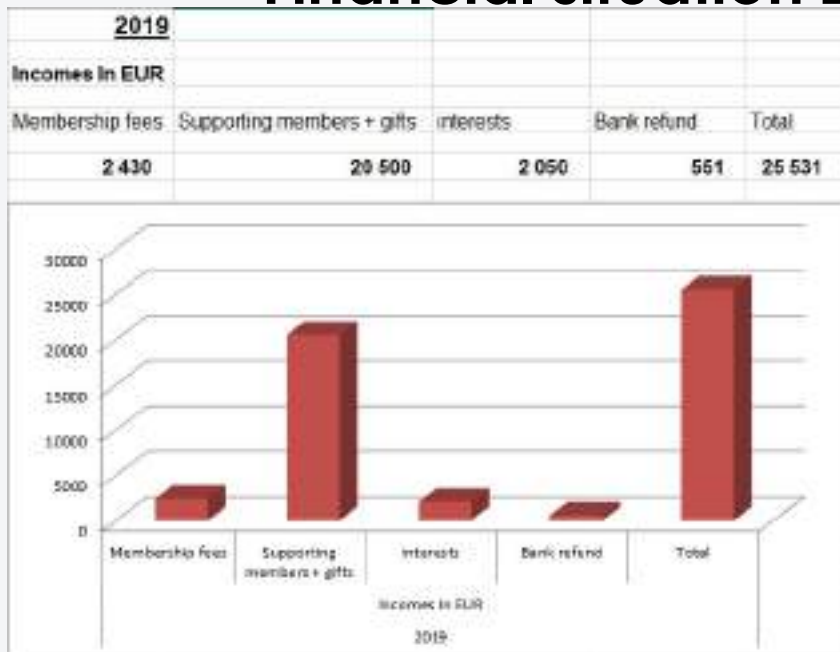


Category	Percentage
Gifts	60%
Producers support	24%
Membership fees	6%
interest	10%

**Today we have
cash for
128.021,06 EUR**



Financial situation 2019



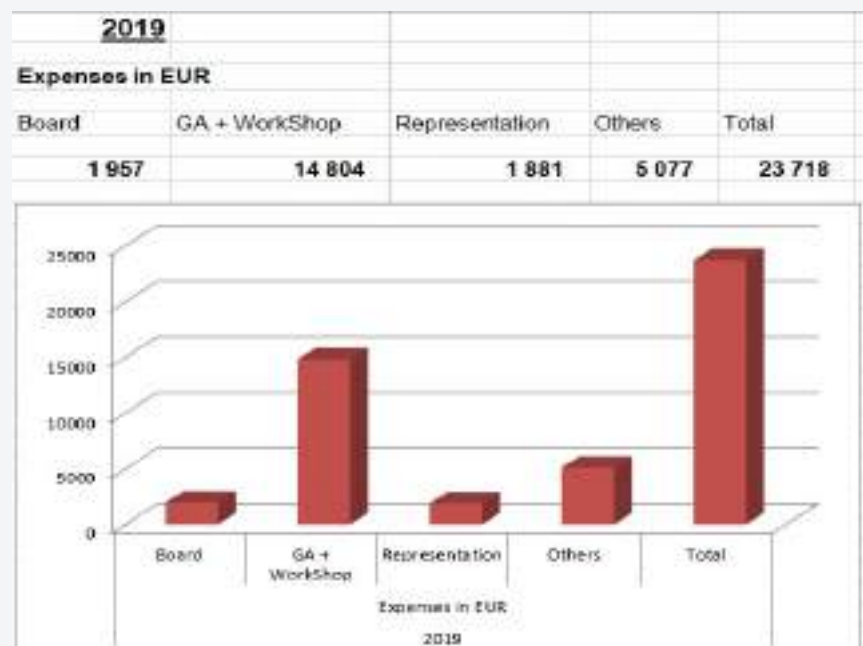
**In the revenues
25.531 EUR**



Financial situation 2019



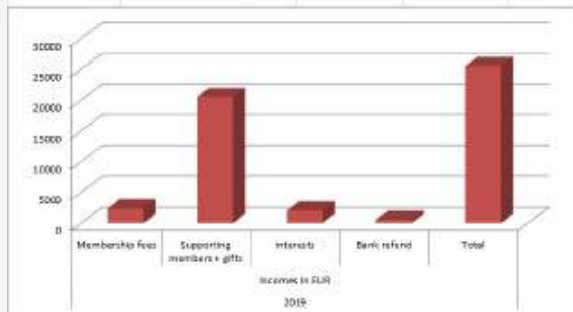
**In the expenses
23.718 EUR
Others for example is
EFW**



Financial situation 2019

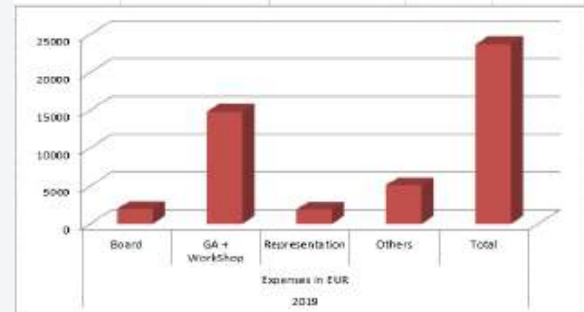


2019				
Incomes in EUR				
Membership fees	Supporting members + gifts	interests	Bank refund	Total
2 430	20 500	2 050	551	25 531



In the revenues
25.531 EUR

2019				
Expenses in EUR				
Board	GA + WorkShop	Representation	Others	Total
1 957	14 804	1 881	5 077	23 718



In the expenses
23.718 EUR



Financial situation 2019



The actual facts :

- 1° - - no more interests on our savings, and for a few years to come
- 2° ++ reduction on our costs in 2019
- 3° ++ reduction on our costs in 2020 and maybe 2021

=> Our revenues will cover our costs for the next 2 years, maybe 3 years

And the future ?

Within 2-3 years, we can hope for a COVID free world

This means that our cost will go back up

Thus, we must think about our future revenues



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AUDIT
Auditors' comments

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Voting only for delegates with rights

VOTING
Approval of the finances

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**Annual Report
2019 & 2020**

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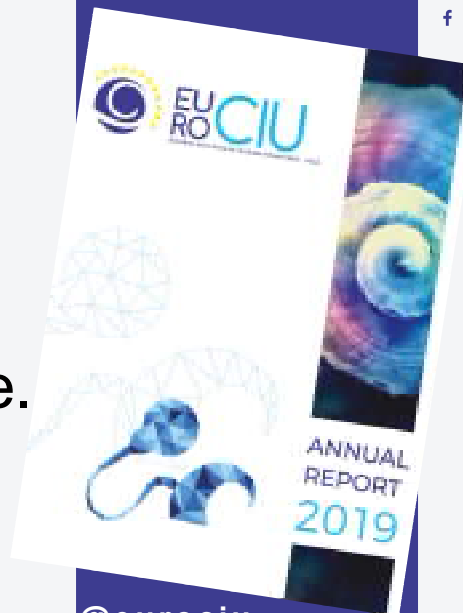
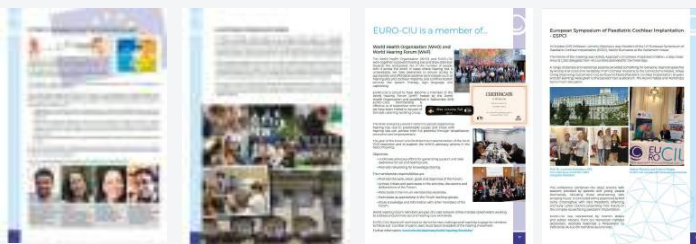
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Annual Report 2019

- ▶ Sent to all associations
- ▶ Available on our website.



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#CochlearImplant



EURO-CIU is a member of...

World Health Organisation (WHO) and World Hearing Forum (WHF)

The World Health Organisation (WHO) and EURO-CIU have signed a joint declaration on the importance of hearing care for all, with a focus on hearing care for children. This declaration is a commitment to working together to improve hearing care for all, with a focus on hearing care for children. It is a commitment to working together to improve hearing care for all, with a focus on hearing care for children.

European Symposium of Paediatric Cochlear Implantation - ESPCI

The European Symposium of Paediatric Cochlear Implantation (ESPCI) is a biennial event that brings together experts in the field of paediatric cochlear implantation. It is a forum for the exchange of ideas and experiences, and for the sharing of best practice. It is a forum for the exchange of ideas and experiences, and for the sharing of best practice.

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Annual Report 2020

- ▶ We need CI user photos.
- ▶ Especially babies and adult users!
- ▶ With permission to use!



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#CochlearImplant



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Voting only for delegates with rights

Approval & Discharge of the Board 2019-2020

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Open floor

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Use the chat box to:

- ▶ Ask questions
- ▶ Give comments
- ▶ Express wishes

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AGA Closing

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Thank you

- ▶ The next AGA will be...
hopefully face to face in
Brussels
- ▶ See you in 2021!

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