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- RELATED CONGRESS - American Cochlear Implant Alliance CI2022 DC Conference on Emerging Issues: Opening Speaker Lou Ferrigno - USA
- RELATED CONGRESS - National Cochlear Implant Users' Association - Summer

Meeting and AGM - UK

- RELATED CONGRESS - HeAL 2022 - Hearing Across the Lifespan - Italy
- RELATED CONGRESS - BATOD National Conference 2022 'Positive Mental Health and Well-being for all' - UK
- RELATED CONGRESS - IFOS World Congress in 2023 - Dubai
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- ADVANCED BIONICS - Introducing the HearingSuccess Portal
- ADVANCED BIONICS - Hearing Loss Jargon: What They Said and What They Mean
- MED-EL - Wearing options for children with glasses and hearing implants
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- OTICON MEDICAL - Notification of Expected Return to Market
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[EURO-CIU's statement concerning the conflict in Ukraine](#)



The board of the European Association of Cochlear Implant Users, EURO-CIU, is deeply concerned by the escalation of fighting taking place in Ukraine. We abhor violence and war. Governments must pursue diplomatic avenues, not take incomprehensible actions with devastating consequences to the civil population.

We ask for an immediate ceasefire, and for all parties to follow International Humanitarian Rights, and the United Nations Convention Rights of Persons with Disabilities (UNCRPD). Minors, vulnerable and disabled persons must not end up paying the highest price.

The use of weapons will cause many more people to suffer the burden of hearing loss. We support and celebrate those who work to reduce the global burden of hearing loss, not those who add to it.

Cochlear implant users require accessible communication. Messages to the population must be available in writing or be captioned so that, for their own safety, persons with hearing loss can follow the instructions in these times of need.

Cochlear implant users also require a continuous supply of batteries and other

consumables for their processors, so that they are not plunged into silence.

We petition to facilitate access to international agencies and humanitarian organisations in Ukraine and its neighbours. We ask EU politicians and citizens to take measures to properly attend to refugees and to take into account their disabilities.

We are proud to say that several of our members have already offered help to refugees fleeing Ukraine to other countries, as well as organizing and providing materials to reach the borders and go directly to people who are suffering. Dear friends, cochlear implant users and families in Ukraine, EURO-CIU, with our 33 members from 23 countries, will do our utmost to support you in any way we can!

From the board of EURO-CIU.

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MESSAGE FROM THE EDITOR



We are continuing to live through difficult times. Just as things were starting to get almost back to normal with Covid being under control, Russia invaded Ukraine. We have people reading this newsletter from both Russia and Ukraine, so our thoughts are with them at this

difficult time. I know that various organisations are sending supplies to Ukraine, particularly to the border with Poland. We also think of our friends in other countries neighbouring Russia and Ukraine, who are also concerned.

It was good to meet up with so many of you on-line for our General Assembly - we are looking forward to the next one being able to meet in person!

Many thanks to those who have sent us articles - it's always good to hear what is happening in our member countries. Also thanks to the cochlear implant companies for keeping us up to date.

Please feel free to forward this Newsletter to Members of Parliament, friends, colleagues and members of your own organisations. We are keen to increase the number of people who can read about the benefits of cochlear implantation. Let's get the message across, particularly as we develop our work, about which you can read in this newsletter.

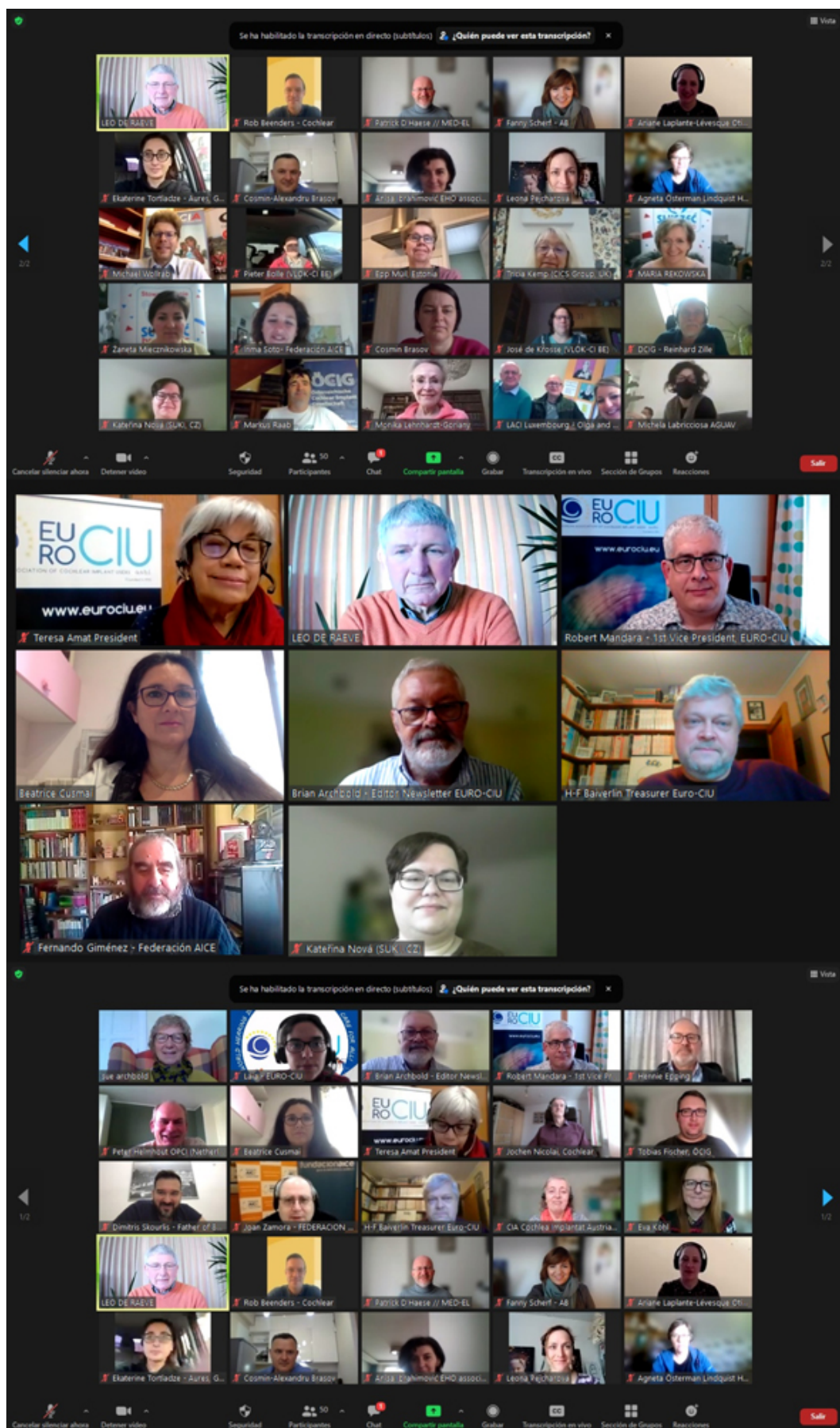
The next edition of the EURO-CIU Newsletter will be due in June, so please let me have your articles (maximum 500 words per article please) and jpg photos by Monday 6 June 2022. Just e-mail them to me at newsletter@eurociu.eu

With every good wish - and have a good Summer!

Brian Archbold (Editor)

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[EURO-CIU NEWS - General Assembly - by Zoom](#)



(Photo: Board and Advisors in the centre block, and others who attended on Zoom)

The General Assembly was held by Zoom, and we were pleased that over 50 attended, from all over Europe. Our Scientific Advisor, Dr Leo De Raeve, was invited to chair the meeting.

The first section related to EURO-CIU's collaboration with other organisations, and there were presentations about [Cochlear Implant International Community of Action \(CIICA\)](#), the [Virtual Lunch Debate](#) at the European Parliament on making listening safe, and the [European Health Forum](#). Further articles on some of these topics can be found later in the newsletter.

We were then delighted to welcome Rob Beenders and Jochen Nicolai (Cochlear), Fanny Scherf (Advanced Bionics), Patrick D'Haese (MED-EL) and Ariane Laplante-Lévesque (Oticon Medical), who updated us on how they were engaging with users and advocacy work.

There followed a discussion on EURO-CIU's ongoing projects, including Why Hearing Well Matters for Healthy Ageing, in collaboration with [CIICA](#).

Henri-François presented the finances, which had been audited, and both the finances and the Board's discharge were passed unanimously.

Other items are covered in the following articles in this newsletter – such as Leo's presentation on CI Statistics, the forthcoming EURO-CIU Symposium and General Assembly in The Netherlands and the election of second Vice President and Secretary.

It will be good to meet up in person in November in Rotterdam.

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[EURO-CIU NEWS - New Vice President - Beatrice Cusmai](#)



At the recent General Assembly, Beatrice (who has been EURO-CIU Secretary since 2018) was elected as second Vice President.

She is a 49-year-old mother of 13 year old twins with bilateral CI and hearing aid. She works as PR & Press office manager for an Italian digital communication company. She is vice president at AGUAV and is a founding member of CIICA.

Beatrice says: *"I'm very pleased to remain on the EURO-CIU Board as second vice president, in order to help the new secretary and to cooperate with the board for future actions. This pandemic time has created great problems all over the world and I still believe that a community of people fighting for the same reason, is more necessary nowadays than ever."*

"Projects for the future of EURO-CIU? I'd like to help young CI users from all over Europe to meet, discover cultures and break down barriers, following the idea of our German association DCIG. Furthermore, I want to fight for the best technology and rehabilitation methodology."

"Then I would really like to create a "European Mapping Academy" to ensure the best maps and CI outcomes because "good mapping" is a huge problem all over Europe. We

can have the best technology, but if it is not fitted properly, it does not produce the best possible outcomes. And this means that “to be able to hear well or not” depends on the mapping technician that fits the CI. This is not acceptable in 2022.”

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EURO-CIU NEWS - New Secretary - Kateřina Nová



Kateřina is a 34-year-old bilateral cochlear implant user from the Czech Republic. She became deaf at the age of 2 due to meningitis, and then received her first CI when she was 12 and second when she was 30 (1999 & 2018).

She likes languages and international cooperation, and also has experience with studying and working abroad (in Germany) which she enjoyed very much. Kateřina is very passionate about cochlear implants in general – she enjoys learning new information about them, sharing her own story and experience, learning other people's experiences, encouraging others to seek options for treatment of their hearing loss, helping them to troubleshoot their issues with the CI etc. She is also a founder and admin of Czech CI users Facebook group, which is quite active, and people there often ask for advice or share their stories.

Kateřina has been a board member in SUKI (Czech association of CI users) for several years now, mostly responsible for administrative tasks – together with other board members they have been working on organizing their regular events, managing their members base and membership fees, sending e-mails with information, or creating newsletters. She managed to get a free license (for non-profit organisations) of Google Workspace for SUKI, so they can use all the features for their organisation.

She believes that EURO-CIU would benefit from having a relatively young CI user on the board who is able to represent and connect with younger CI users, feeling that it is necessary to make young CI users aware of EURO-CIU and motivate them to participate in advocating for matters which concern them. Kateřina would like to help with spreading awareness about cochlear implants and with improving the conditions for cochlear implant users so that as many people as possible have the access to the hearing technology and support that they need.

Kateřina says: "I also believe in international cooperation. We can always learn from each other and help each other. This way we can all benefit from the shared knowledge and experience."

Projects in which Kateřina has been involved include:

- Encouraging communication and meetings of young and adult CI users on both local and European level;
- Supporting sensible processor replacement intervals in all European countries so that CI users have good and affordable access to the newest technology;
- Promoting cochlear implants (ideally bilateral) as a standard care for severe/profound hearing loss in all age groups.

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[EURO-CIU NEWS - The board thanks Sue and Brian Archbold for their amazing support](#)



The Board of EURO-CIU would like to express our gratitude to Sue and Brian Archbold for the amazing support that they provide to EURO-CIU.

At very short notice, Sue generously enabled EURO-CIU to use her Zoom account to run the General Assembly, and arranged for Lisa Cordaro of [Stella Communications](#) to provide Speech to Text in a number of languages. There are unknowns and uncertainties when arranging any event, and this one was no exception. Sue travelled to Spain for a holiday on the evening before the General Assembly and we were all very nervous about whether the internet connection there would be strong enough to support the Zoom event! In the weeks, days, hours and minutes leading up to the General Assembly, emails were flying back and forth, huge files being transferred, online meetings being held – the only time Sue seemed to stop was when she was in the air! The board arranged for flowers to be

delivered during the event, but did not know exactly when they would be delivered. As luck would have it, the doorbell rang while Sue was on camera, so we all got to see the beautiful moment when she received them. Thank you Sue for everything you did to make the General Assembly a success!

Meanwhile, this newsletter is the 50th one that Brian has edited as a volunteer for EURO-CIU, and we want to acknowledge this amazing milestone. Four times a year, Brian quietly and without fuss gets on with calling for articles and photographs, assembles them into order, edits them, adds links, puts them through a proofing round, patiently handles the requests for changes from the board, publishes the PDF, and then mails them to our subscribers in such a way that they do not get caught in spam folders. It takes far more time and effort than most people realise to pull everything together. Under Brian's editorship, the newsletters have become hugely valuable resources for all EURO-CIU members and reach an ever-growing global audience. Thank you Brian and please keep up the excellent work!

Robert Mandara on behalf of the EURO-CIU Board

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EURO-CIU NEWS - International Cochlear Implant Day Manifesto 2022



February 25th: 14 years celebrating International Implant Cochlear Day:

During this period where the changes in our environment have been enormous, specifically for CI users, and for people with impaired hearing, enormous barriers to communication have appeared, particularly the use of opaque masks, which prevent lip-reading.

All of us have been affected by the new social and communicative customs, but young CI users in education and the labour market have been particularly affected, by having to use masks or rely on video calls for education or online meetings.

Poor lighting, backlighting, background noise from refrigerators or washing machines in teachers' homes or work teams have presented continuous problems for people with hearing loss. Today, accessibility through technology is more important than ever and we're all trying to adapt to it. Nevertheless the elderly population are getting left behind.

The situation in which we are immersed causes a lot of frustration and concern stemming from social isolation and the isolation that the digitization of our environment entails. That is why, at EURO-CIU, we are working to eliminate barriers to communication and information.

In 2022, we have chosen four protagonists of different ages as representatives of the Cochlear Implant Day celebration. Each age has its specific needs and we want to make them all visible, thereby reducing the stigma of deafness.

The health situation is causing longer waiting lists for cochlear implant surgeries and delaying processor renewals due to a lack of resources. In some places, rehabilitation

services, which allow users to get the most out of their devices, are being closed.

Communication is what connects us to the world. Unaddressed hearing loss causes isolation and depression, and accelerates cognitive decline, dementia, etc. in later life, requiring additional public sector spending in the long term.

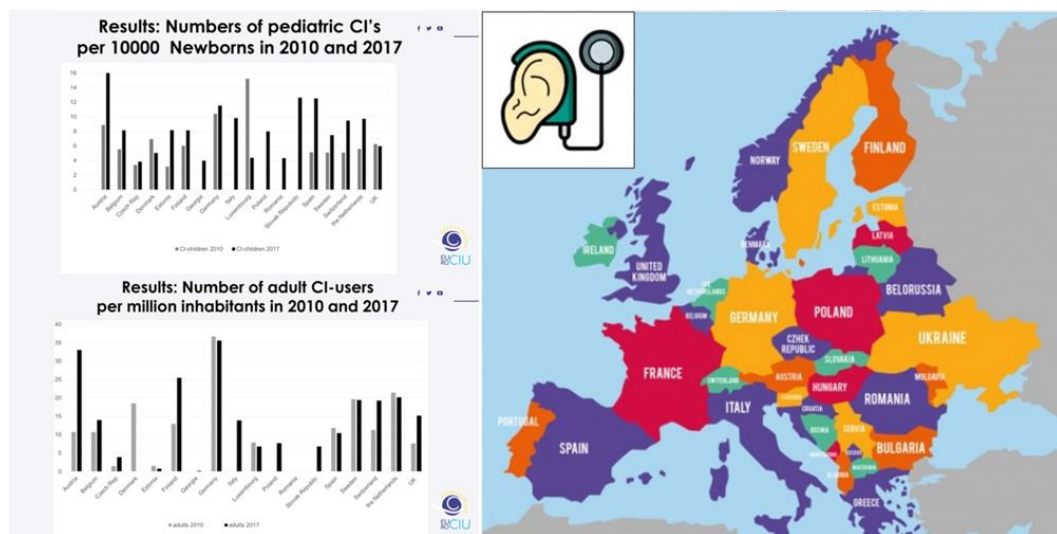
Faced with the great problems we have, we must remember that investing in hearing is investing in people's quality of life. We must continue to advance, to claim our position in society, with equal opportunities.

Nothing and no one will prevent us from communicating! Happy International Implant Cochlear Day!

#CochlearImplant #CochlearImplantDay #CIDay

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EURO-CIU NEWS - CI-statistics EURO-CIU in 2017



(Figure 1 at top left, and Figure 2 at bottom left)

In 2020, Leo De Raeve, scientific advisor of EURO-CIU, carried out again a small survey collecting data on the number of CI-patients in European countries in 2017. These data surveys are always very important for EURO-CIU because it shows us the evolution in the number of CI-users in Europe as a whole and in each country separately. Often these data are also very useful for our actions.

Also, this time, several member states had problems in collecting these data, but finally 18 countries were able to deliver us their data: Austria, Belgium, Check Republic, Denmark, Estonia, Finland, Georgia, Germany, Italy, Luxemburg, Poland, Romania, Slovak Republic, Spain, Sweden, Switzerland, the Netherlands and UK. These 18 countries were representing 125,668 CI users. **So, we can estimate that EURO-CIU represents more than 200,000 CI-users in Europe.**

Looking at the number of paediatric CI-users ([figure 1](#)), 11 out of the 18 countries show in 2017 data above **8 CI-children per 10,000 newborns in comparing to only 3 out of 13 countries in 2010**. This means that several countries have made a tremendous step forward during the last decade concerning their numbers of paediatric cochlear implantation. We also see in all countries (except Denmark, Luxembourg and UK) an increase between 2010 and 2017, in the average yearly number of paediatric CI-users.

On the other hand, the **adult data** ([figure 2](#)) from 2017 are less homogeneous than the paediatric ones and they show us huge differences between the countries. In Austria and Germany 35 persons per million inhabitants receive yearly a CI. In comparing to this in

Belgium, Czech Republic, Georgia, Italy, Luxembourg, Poland, Romania, Slovak Republic and Spain, less than 15 persons per million inhabitants receive a CI (less than half of the numbers from Austria and Germany).

In comparing to 2010 there was only a big increase in the adult numbers in Austria, Finland, Switzerland and UK, but in the other countries there was only a small increase or sometimes even a decrease.

We can conclude that in general there is in Europe a positive trend concerning the numbers of paediatric cochlear implantation in children, but this is not the case concerning adult cochlear implantation.

So, in many countries we have to focus and raise more awareness on adult hearing loss and adult cochlear implantation. The Spend-2-Save document, created and supported by EURO-CIU, is a good example of a resource which can be used in actions to raise awareness on adult cochlear implantation.

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[EURO-CIU NEWS - World Hearing Day 2022](#)

World Hearing Day
3 March 2022



To hear for life, listen with care!



**Hearing loss due
to loud sounds can
be prevented**

**It is possible to restore
hearing function:
Can you hear us?**

#CochlearImplant

LEARN MORE



Make Listening Safe

#worldhearingday | #hearingcare | #safelistening

Over 1 billion people aged 12 to 35 years risk losing their hearing due to prolonged and excessive exposure to loud music and other recreational sounds. This can have devastating consequences for their physical and mental health, education, and employment prospects.

On World Hearing Day 2022, under the theme **To hear for life, listen with care!** WHO has issued a new international standard for safe listening at venues and events. The standard applies to places and activities where amplified music is played.

"Millions of teenagers and young people are at risk of hearing loss due to the unsafe use of personal audio devices and exposure to damaging sound levels at venues such as nightclubs, bars, concerts and sporting events," said Dr Bente Mikkelsen, WHO Director for the Department for Noncommunicable Diseases.

She added: *"The risk is intensified as most audio devices, venues and events do not provide safe listening options and contribute to the risk of hearing loss. The new WHO*

standard aims to better safeguard young people as they enjoy their leisure activities.”

New recommendations to limit risk of hearing loss

The Global standard for safe listening at venues and events highlights six recommendations for implementation to ensure that venues and events limit the risk of hearing loss to their patrons while preserving high-quality sound and an enjoyable listening experience. The six recommendations are:

- (1) a maximum average sound level of 100 decibels
- (2) live monitoring and recording of sound levels using calibrated equipment by designated staff
- (3) optimizing venue acoustics and sound systems to ensure enjoyable sound quality and safe listening
- (4) making personal hearing protection available to audiences including instructions on use
- (5) access to quiet zones for people to rest their ears and decrease the risk of hearing damage; and
- (6) provision of training and information to staff.

The new standard was developed under WHO's Make Listening Safe initiative which seeks to improve listening practices especially among young people, drawing on the latest evidence and consultations with a range of stakeholders including experts from WHO, government, industry, consumers, and civil society.

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EURO-CIU NEWS - Virtual Lunch Debate

WHO Global Standard for Safe Listening Venues & Events

1. Limiting sound levels
A maximum limit of 100dB L_{avg} 15 minutes* is imposed, keeping sound safe and enjoyable for the audience.

2. Monitoring sound levels
Live monitoring and recording of sound levels using calibrated measurement equipment by designated staff members.

3. Optimizing venue acoustics and sound systems
The sound system and venue acoustics should be optimized to ensure enjoyable sound quality and safe listening levels for all.

WHO Global Standard for Safe Listening because you need to ensure good sound quality, and also a design that makes it

Participants (192)

- Panelistas (9)
- Espectadores (183)

Zoom Seminars web

12:59 03/03/2022

Zoom Seminars web

14:00 03/03/2022

The WHO Global Standard for Safe Listening Venues & Events

Mark Laureys
AEA – European Association of Hearing Aid Professionals
WHO – Make Listening Safe Workgroup
Thomas More University College – Department of Audiology – Antwerp

And then you will also hear in the last presentation from WHO Europe.

It is a yearly tradition that the European associations of Hard of Hearing People, Hearing Aid Professionals and Hearing Aid Manufacturers in strong cooperation with the World Health Organisation, organise a Lunch Debate in the European Parliament in Brussels, in order to celebrate "World Hearing Day". This year the theme was "To hear for life, listen with care!" The event was hosted by MEP Alex Agius Saliba (Malta, S&D).

Mark Laureyns, AEA President, managed the event and he thanked all the speakers for their great contributions, noting that 220 people attended on-line.

The handouts, the links to all the separate videos and to the full debate (including the discussion and conclusions) are available as follows:

Virtual Lunch Debate Video 01 - Welcome & Introduction – MEP Alex Agius Saliba (Malta, S&D) <https://youtu.be/OV4H7wQHEmM>

Virtual Lunch Debate Video 02 - The WHO introduction on "To hear for life, listen with care" - Shelly Chadha WHO <https://youtu.be/kC0Ilw0RSL4>

Virtual Lunch Debate Video 03 - The "Make Listening Safe" workgroup and the "WHO Global Standard for Safe Listening Entertainment Venues" – Mark Laureyns - AEA <https://youtu.be/6ce3VnVASZE>

Virtual Lunch Debate Video 04 - Why hard of hearing people care for safe listening – Lidia Best– EFHOH <https://youtu.be/ehDeh1mpgBk>

Virtual Lunch Debate Video 05 - Why and how the organisation of Cochlear Implant users, started a program of Young Ambassadors going to schools to promote safe listening – Laia Zamora - EURO-CIU <https://youtu.be/Tq8QezLTpGo>

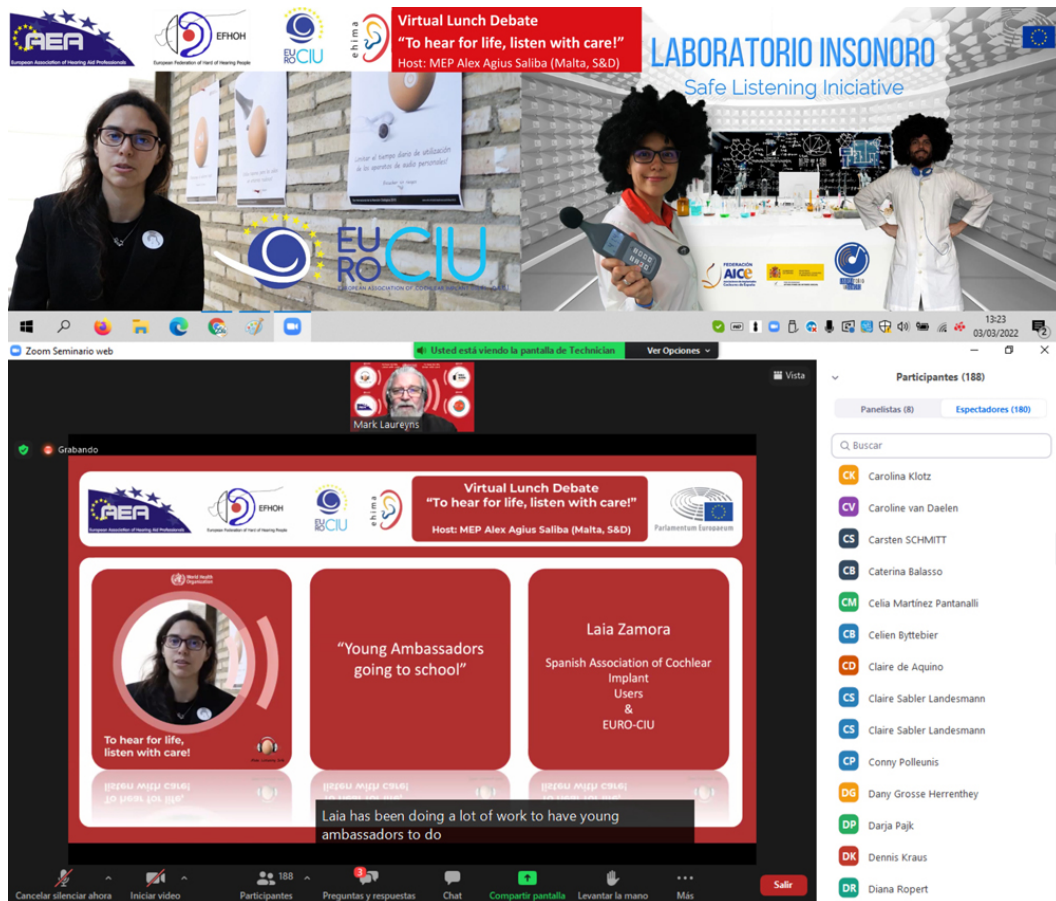
Virtual Lunch Debate Video 06 - "The importance of Adult Hearing Screening" - Patrick D'Haese - Hear-it <https://youtu.be/CKZSZE9HrUM>

Virtual Lunch Debate Video 07 - "The importance of Access to Ear and Hearing Care in Europe" - Satish Mishra – WHO-Europe <https://youtu.be/EEtXI5tasJ8>

Full Lunch Debate including the Debate and Conclusions: <https://youtu.be/Zadf7xtz-Fs>

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[EURO-CIU NEWS - Virtual Lunch Debate - Young Ambassadors Program](#)



Why and how the organisation of Cochlear Implant users, started a program of Young Ambassadors going to schools to promote safe listening

We should all be proud of Laia Zamora, our EURO-CIU member, who presented this topic extremely well at the European Parliament Lunch Event on 3rd March.

The Young Ambassador Programme is not only a method to promote Safe Listening to the general student body, but also to improve Cochlear Implant and Hearing Loss information between students and education. Additionally, it brings visibility to accessibility communication barriers and the invisibility of the psychological bullying some people with disability and especially hearing loss and cochlear implant users suffer. All that done in a way that is funny and approachable to teens.

Watch Laia's presentation here: <https://youtu.be/Tq8QezLTpGo>

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[EURO-CIU NEWS - 13th European Symposium of EURO-CIU: Cochlear implants now and in the future: What do we know and what can we expect?](#)



Photo: Postillion Convention Center Rotterdam (the Netherlands)

11-12 November 2022 Rotterdam, the Netherlands

OPCI (CI-users association-the Netherlands) and ONICI (Independent Information Centre on Cochlear Implants-Belgium) are pleased and honoured to invite you to the 13th European congress of EURO-CIU entitled 'Cochlear implants now and in the future', which will take place in Rotterdam, the Netherlands on 11 & 12 November 2022. On Friday 11 November 2022, the EURO-CIU congress and on Saturday 12 November 2022, the general assembly of EURO-CIU will take place in the Postillion Convention Centre of Rotterdam (see photo).

CI users themselves will play an important role at this conference, as one out of three of the presenters will be CI-user or parent of a child with a CI. These International experts in the field of Cochlear Implants will explore several interesting topics related to 'Cochlear implants now and in the future':

- Impact of hearing
- Advocacy work for cochlear implantation
- Rehabilitation after cochlear implantation in adults and children
- Impact of cochlear implantation on brain and cognition
- Hearing loss, communication effort and missing incidental learning
- Future developments in cochlear implantation
- Enjoyment of music with your CI

Rotterdam is easily accessible by plane, car and train.

If you have questions, don't hesitate to contact us at: info.eurociucongress2022@onici.be

We look forward to welcoming you in Rotterdam on 11-12 November 2022.

Hennie Epping, Peter Helmhout, Henk van Rees & Leo De Raeve

The EURO-CIU 2022 steering group, a joint initiative of OPCI and ONICI

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[EURO-CIU NEWS - Global Task Force calls for consistent standard of care](#)

guidelines for adults with cochlear implants



There is currently no standard of care for adult cochlear implantation

This project aims to create living practice guidelines that can be adapted and adopted in country, to optimise the care for adults eligible for cochlear implants

Find out more at www.adultheating.com

 CI TASK FORCE

The formation of a new global Task Force was announced on International Cochlear Implant Day, marking the next step in the creation of 'Living Guidelines' to set the standard of care for adult cochlear implantation (CI).

The project goal is to create global living practice guidelines and guidance that can be adapted and adopted in each country, to optimise the standard of care for adults eligible for CI. As 'living' guidelines, they can be updated continuously as new evidence becomes available, as a real-time repository of guidelines under the governance of the Task Force.

The independent Task Force consists of cochlear implant users and key hearing experts from surgical and audiology backgrounds, representing more than 22 countries. The Task Force will engage with the Cochlear Implant International Community of Action (CIICA), representing cochlear implant users, other consumer organisations and professional societies to ensure the perspectives of adults with hearing loss are included in the process.

The Task Force has three Co-Chairs:

- Leo De Raeve: Scientific Advisor of EURO-CIU, Acting Chair of CIICA (Cochlear Implant International Community of Action) and Director of ONICI (Independent Information and Research Center on Cochlear Implantation);
- Meredith Holcomb: Director, Hearing Implant Program, University of Miami, Miller School of Medicine, Department of Otolaryngology;
- Ángel Ramos Macías: Professor, University of Las Palmas. School of Medicine, Department of Otolaryngology – Head and Neck Surgery and Maxillofacial.

To view more information on the Living Guidelines Project, including methodology and objectives, [click here](#).

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[Cochlear Implant International Community of Action \(CIICA\) - First Anniversary](#)



Celebrating CIICA's First ANNIVERSARY: International CI day 2022 The Impact of the Pandemic

International Cochlear Implant (CI) Day, 25 February, was also the first anniversary of CIICA, the CI International Community of Action. In one year, CIICA's network has grown to 79 organisations, and 370 individuals from 52 countries across the globe, united in the goal of increasing access to cochlear implantation and lifelong services for all those with hearing loss who can benefit.

Huge thanks to all the members of EURO-CIU who have been so supportive to this initiative – and as Teresa Amat, President, said: *“The synergies of the network members have far exceeded our expectations in the first year.”*

To celebrate our Anniversary, we asked for video messages about the Impact of the Pandemic – we had some great thoughtful responses which pointed out the challenges – but also what we have learnt. Thanks to PINDROP, New Zealand we have a great compilation video on the impact of the pandemic on our home page: www.ciicanet.org, and the individual videos at www.ciicanet.org/news from across the globe.

As Robert Mandara, Vice President of EURO-CIU said *“The pandemic forced me to confront and overcome my fears of video calls.”* Many of us could relate to that and what we have learnt over the past two years! Darja Pajk, of EFHOH, made the point that *“Perhaps more people will understand the problems of people with hearing loss”* having experienced difficulties in communication, and Ingeborg Dhooge of Belgium encouraged us to remember that *“People are resilient, are creative and look for solutions.”*

Our CIICA LIVE event for International CI day and our Anniversary followed up the topic of The Impact of the Pandemic- hearing from users, families and service providers; again, really thoughtful presentations about moving on with services differently in spite of the challenges. All presentations are available at [CIICA LIVE: The Impact of the Pandemic on CI users, Families and Services – CIICA \(ciicanet.org\)](http://www.ciicanet.org). Accessibility is important to us: all our events have live captioning, with translations into other languages on request. Our website has over 40 languages available and many of our resources are translated into other languages by members.

A recent innovation has been our CIICA Conversations where a small group has a lively conversation for one hour to explore a specific topic; these have included tele-practice and the impact of the pandemic. A summary of the issues which emerge is then available for further comment on the website. Importantly, young people are also part of this conversation; read Zahra's lively account of the conversations! As Bowen Tang, President of International Federation of Hard of Hearing Young People said: *“Our technology has to last a lifetime and we have to build a relationship with our CI”* See [FULL: CIICA CONVERSATION: Life with CI: 18-30's in Conversation: Together we can shape our future – CIICA \(ciicanet.org\)](http://www.ciicanet.org) for the summary of their shared issues.

The pandemic has made us all aware of the huge value of communication in our lives and for those with hearing loss the technology of CI can be key to communication and connection with other people. CIICA will continue to ensure that cochlear implantation remains at the front of health care decisions, even in challenging times, and join the activity to support the efforts to support refugees from Ukraine with hearing loss. Hearing and Communication is even more important in a crisis.

Visit www.ciicanet.org to see our global activities.

(Note: EURO-CIU is a Founding Member of CIICA and Teresa Amat is a member of the Steering Group)

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Cochlear Implant International Community of Action's (CIICA) conversation on 'Life with CI, shaping our future'



Pacing back and forth between my suite and the laundry room on campus to keep myself awake at 3 am is not my normal routine, but I was pumped with excitement to join Cochlear Implant International Community of Action's (CIICA) 18–30-year-old conversation on 'Life with CI, shaping our future.'

My name is Zahra, I was born profoundly deaf and wear bi-lateral cochlear implants – receiving my first implant in my right ear when I was 20 months old and a subsequent one when I was 6. Robert Mandara (Vice President of EURO-CIU), who I met 4 years ago at 'European Friendship Week' camp recommended I attend this and I was immediately intrigued by the opportunity to meet other implant users like myself – this was my first time partaking in one of CIICA's events.

During the introductions, I was pleasantly surprised to not only see such a diversity of ages but also the scope of countries in which these other CI users lived – across 4 continents (Asia, Europe, North and South America)! The conversation was guided by facilitators and opened a safe space to discuss the challenges we face collectively with topics including sports, governmental accessibility rules during the pandemic, and personal resilience.

The conversation took place over ZOOM and there was access to a live palantypist allowing us to follow along or catch up on anything we may have missed. The feeling that I could attend a ZOOM call, knowing that my accessibility needs would be automatically catered for because the CIICA team were aware of the requirements to support d/Deaf and Hard of Hearing individuals was so reassuring and alleviated the stress I feel when having to participate in online meetings.

I had so much I wanted to share because I empathised with all that was being discussed as it was relevant to me personally. Having recently moved to Singapore for university, I have sometimes felt socially excluded and much more aware of the challenges my deafness presents with the use of masks everywhere and not knowing many other d/Deaf people or CI users. However, this conversation, although only 1 hour and taking place virtually, alleviated some of these feelings of isolation and was liberating in so many ways. At the end of the session, we shared contact details with one another, strengthening bridges of engagement within the cochlear implant world.

As Robert Mandara, VP of EURO-CIU, from Finland, comments: *“By accepting and committing to the declaration, the Nordic region will be set to lead the world in providing comprehensive, sensible and fair cochlear implant provision for adults. Cochlear implants are life-changing sound investments, restoring good hearing to most severely and profoundly deaf adults who strive to hear.”*

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CZECH REPUBLIC - SUKI - Informational campaign



Informational campaign about hearing and cochlear implants took place in the Czech Republic between the two important dates: International Cochlear Implant Day, 25th of February, and World Hearing Day, 3rd of March

The Czech patient organization SUKI followed up on its successful campaign of the last year and organized a big educational campaign called Haló, slyšíme se? (Hey, do you hear me?) aiming to address the adolescent and adult population with hearing loss. The purpose of the action was to raise awareness of people with hearing loss about the possibilities of compensation. The number of implanted adults with severe hearing loss in the Czech Republic is still very low compared to west european figures.

We decided to run a series of lectures, media speeches, webinars and other events between February, 25th and March, 3rd 2022 in close collaboration with the Czech ENT society to raise awareness about the need for compensation and the huge benefit of CI. More about the campaign (unfortunately just in Czech language [here](#)).

The campaign was crowned by a very special social event called SUKI děkuje (SUKI thanks to..). It took place on the evening of the World Hearing Day and was connected to the WHO campaign, [To hear for life listen with care](#). This event included four lectures led by our significant professionals. They talked about human hearing and risks that it can face during life, what are the possibilities for those whose hearing is damaged, but also about the process of getting CI and subsequent rehabilitation. At the end of the event, SUKI awarded five people to thank them for their contribution to the quality of life of CI users in the Czech republic over the past 30 years.

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A few days ago, we celebrated International Cochlear Implant Day and World Hearing Day. Both days are known in Georgia and more and more organizations celebrate them. This year, on their own initiative, more parents congratulated each other on International Cochlear Implant Day. Both days are very precious to me, and I am very happy and proud that it was I who first celebrated them here in Georgia and contributed to their popularization.

This year we were also preparing and planning. Ukraine was also preparing and planning. This year, for the first time, WHO material was prepared in the Ukrainian language. And it is the effort of our member - Ukrainian association for CI Users and Maks Teriushin. My respect to him.

But today I am powerless. For the first time I feel that all this has faded into the background, and today I have the same feeling of war as our friend Ukraine. Ukraine today is fighting to protect its homeland, its home, and its lives from the evil empire. Ukraine is fighting for me, for my country, and for the entire free world.

I don't know what I can do today. How to express my support in addition to the fact that we, as Aures, issued a statement and expressed solidarity, in addition to the fact that we are all united in our attitude, we stand at street rallies and say that this must end. Georgians are in solidarity with his concrete actions. Hotels, ordinary citizens gave shelter free of charge to all citizens of Ukraine who were here and can't return to home, etc. But what can I do but shed tears, sleepless nights and pray? What can we do as a community?

We know that you are all concerned, we know that you support Ukraine. And here, in

Georgia, we feel exactly what our Ukrainian sisters and brothers feel.

I am not a Soviet citizen, I am a Georgian, and today I am a Ukrainian too. I was born in the Soviet Union, in the Russian Empire. Who, if not us, knows what Russian aggression is, who, if not Georgia, knows what war is? Not the terrible war that the world survived and defeated evil together several decades ago, which no normal and free nation would agree to repeat, not the war that I saw only in the movies. No, I'm talking about the war that has plagued my country since the 1990s. Even today, part of Georgia is occupied and is a victim of Russian aggression. Even today people are kidnapped and killed.

Today everyone should know that this is not a Russian-Ukrainian conflict, it is not a conflict at all. This is a real fascist war that recognizes neither children, nor the people with disabilities, nor the elderly, a war that does not recognize rules. It destroys schools, kindergartens, hospitals. That kills civilians.

I don't want war! and Ukraine does not want it! Normally, nobody wants war!

We do not know the situation of children or adults in Ukraine who use CI or hearing aids. For example, if they still have batteries, can they have their devices in order that connect them to the world? What kind of needs do they have?

Please, forgive me for my emotions. I have no other weapon than to scream wherever my voice can go. Today Ukraine needs solidarity, and I think that together we can support our Ukrainian friends, express solidarity, and tell the world that all our communities are in solidarity, we want to live in freedom, respect the rights of humans and just do our job, make the world a better, inclusive, accessible, protect the rights of people with hearing loss. Let's take care of our children for a better and more equal world.

Ekaterine Tortladze

On behalf of the Aures Foundation

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THE NETHERLANDS - OPCI conducts survey to measure satisfaction of CI-wearers



Every five years OPCI (Independent Platform for Cochlear Implantation in the Netherlands) conducts a survey to measure the satisfaction of CI wearers. The last time was in 2016. At the end of 2021, OPCI did it again. This ensures the possibility of comparing results.

482 people completed the survey. Although there have been about 8,000 implantations in the Netherlands, these figures still give a good impression of the experiences of CI wearers. The response rate with comparable surveys was called very good by the research bureau.

The average age at implantation for adults is 58.8 years. For young people up to 18 years of age it is 4.8 years.

Approximately half of the adults use a hearing aid in addition to their CI. In young people, this is only 16%. It should be noted that young people in the Netherlands are eligible for bilateral implantation (58%). This is not the case for adults (7%). Both adults and youngsters are satisfied with their bilateral hearing (96% and 82% respectively).

Satisfaction

Among adults, 86% are satisfied to very satisfied, 11% are neutral and 3% are unsatisfied to not satisfied. In young people, 100% are satisfied or very satisfied.

When it comes to speech intelligibility, the percentages are somewhat different: 85% of adults and 78% of young people are satisfied. These percentages are slightly lower than in 2016. The fact that speech understanding in noisy surroundings is less appreciated is a given.

Satisfaction with the rehabilitation programme after implantation is very high in both groups.

There is a big difference in satisfaction with listening to music between adults and young people: 46% versus 89%. Undoubtedly, this has to do with the fact that many young people have heard music via their CI from an early age. Adults have had to learn this all over again.

In both age groups, around 75% use assistive listening devices. Many options are mentioned, such as loop systems, solo devices, Dutch sign language (NGT), Dutch with supportive gestures (NmG), and other accessories.

Work

For those in paid employment, about half of the respondents indicated that their work and everything that goes with it has remained more or less the same. The other half indicate that this has improved or become much better.

On the social front (family, clubs, activities), 10% say they have stayed the same. All the others said they were better, much better or very much better. Less than 10 % of those surveyed say it has become less for them.

The quality of life is experienced as less by only 6%. The vast majority therefore say they can live better, much better or very much better.

Problems

The vast majority of respondents said that they had not experienced any physical problems after implantation. Problems with the processor were also rare. When they did, help from the CI centre was almost always forthcoming.

Problems with the implant are also rare. In adults, even less than in young people. Reimplantation has taken place in all cases.

The CI centre

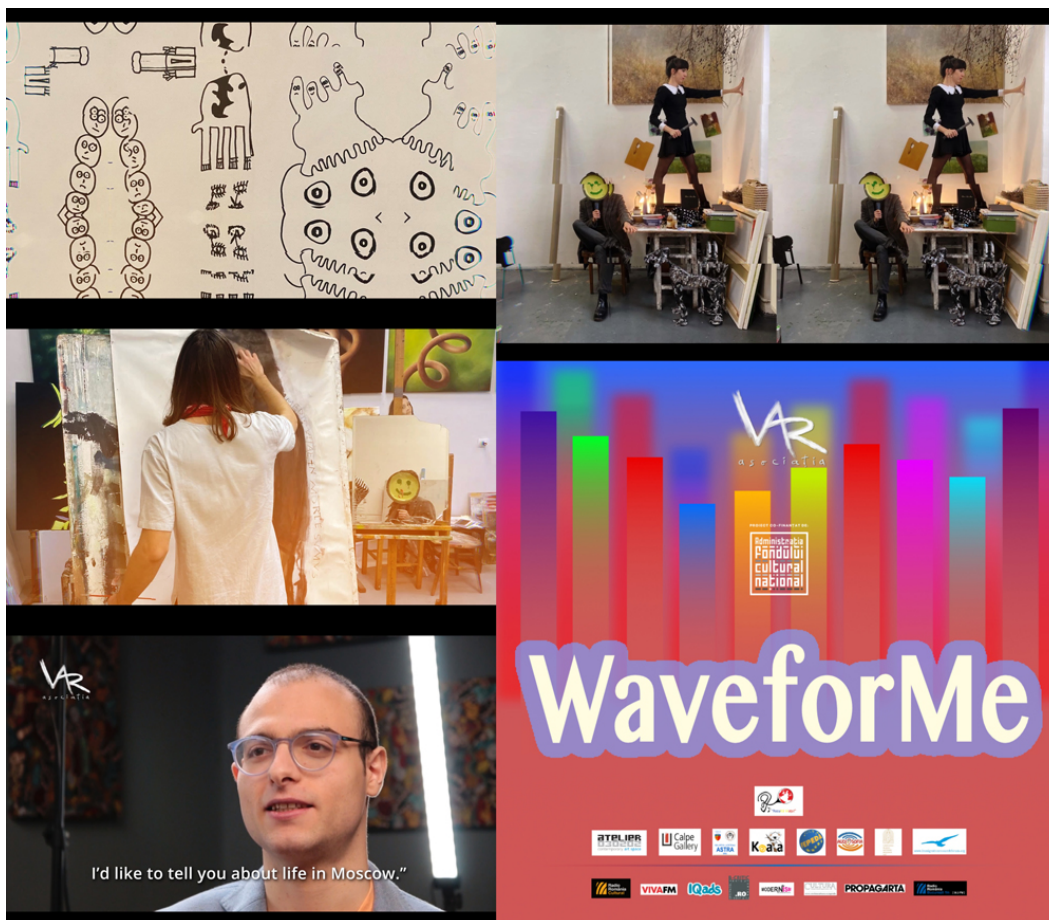
Over 85% of all respondents are satisfied to very satisfied with the CI centre they deal with during the operation, rehabilitation and aftercare. 12% are neutral about it and 3% are not to very dissatisfied.

Fortunately, if we look at the whole picture, we can still see that people with a CI are very satisfied. In some sub-areas, this satisfaction is a little less than in 2016, but that does not result in significant differences.

The entire survey can be found at <https://www.opciweb.nl/opci-enquete-2021/>

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ROMANIA - ASCULTĂ VIAȚA - WaveforMe



On behalf of WaveforMe team, I'm pleased to announce that our first WaveforMe podcast is officially live across the website Waveforme - <https://waveforme.org/podcast/>.

The online platform is intended to become a perpetual hub for such collective targeted contributions benefiting the target youth group and a focal point for all stakeholders.

Please find here a brief description of our education through culture and creativity project "Waveforme". The project is a bilingual (English/Romanian), cultural, educational and social activism online platform (work in progress) dedicated primarily to hearing-impaired preadolescents and youth wearers of cochlear implants/hearing aids, living in Romania and abroad. During the next six months, we target the development of a multi-prong intervention:

1. **Social – developing and disseminating videos (podcasts)** with hearing impaired adults, wearers of cochlear implants/ hearing aids, who live in Romania and abroad, professionals with expertise in arts and culture.
2. **Education – implementing three workshops** in Public Speaking, Visual Arts and Music, each unfolding in five sessions with the participation of 24 selected hearing-impaired Romanian adolescents ages 14-18.
3. **Cultural – creating a virtual gallery**, a public space dedicated to the target beneficiaries and consisting of participants' contributions throughout the workshops and other artwork **submitted after an international open-call**.

The final stage of the "artivism" project involves a traveling exhibition consisting of the curated virtual gallery materials and a storyline for the online platform. This physical

exhibition will be hosted and open to the public in four major cities: Sibiu, Timișoara, Iași and Bucharest.

For those willing to share the podcast and upcoming materials with your audience, please be informed that we meet all legal requirements in regards to intellectual property rights and the use of personal data and images.

Please let WaveforMe Team know if you have any questions about the episode or project at all. I'm happy to help.

Best regards,

Cosmin & WaveforMe team

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[SPAIN - Exposition - History of the Cochlear Implant and Federation AICE](#)



In 2021 the Federation of Associations of Cochlear Implants of Spain, celebrated its 25th anniversary and therefore, Federación AICE has created the travelling exhibition "History of the Cochlear Implant and Federation AICE" with the intention to be exhibited in various

parts of the Spanish geography during 2022, as has already been done in Barcelona, Granada, Seville and Zaragoza.

10 roll-ups / banners summarize the story evolution with curiosities and include QR codes, which greatly expand the information contained in the exhibition with more visual, texts, images and videos subtitled.

You will be able to see the progress of the miniaturization of processors from 1972 to the current ones, as well as learn interesting information about the cochlear implant history, learn about the campaigns to raise awareness on deafness and cochlear implant or break the barriers of communication and promote accessibility, as well as achievements reached are taken for granted today. We have to thank Federación AICE for the struggle during the last 25 years as the representative entity of the cochlear implants, with the collaboration of families, teams of the implantation centres and hospitals, speech therapists, programmers, rehabilitators, manufacturers and, how could it be otherwise, by officials of public administrations like health, culture, education, labour, social affairs, etc.

You can check it out online: <http://implantecoclear.org/exposicion25aniversario>

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SPAIN - Transportation / Illumination Campaign



From 25th February, International Cochlear Implant Day, to 3rd March, World Hearing Day, Federación AICE with collaboration from administrations and transport companies, celebrated the "Hearing Week".

We did events with Hospitals, like in ORL Clínico de Granada who has reached 1,500 CI surgeries or the ENT Service Hospital Son Llàtzer from Palma de Mallorca and the Aragón ENT Cochlear Implant Unit who did press releases and were recorded on local TV stations.

Several transport companies published information, posters and videos about Cochlear Implant, Hearing Loss and Safe Listening initiatives, and municipalities collaborated putting up several posters in their towns and cities buildings and libraries about hearing loss as well as illuminating their monuments, (in violet for CI day and in red for World Hearing Day) to raise awareness about the cochlear implant and giving voice to the hearing loss population.

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WORLD NEWS - AUSTRIA - Safety of Magnetic Resonance Imaging in



Prof Wolf-Dieter Baumgartner

EXCELLENCE dedicated to HEARING IMPLANTS

The HEARRING Group is an independent network of world leading centres and experts dealing with all aspects of hearing disorders. They believe that advancements in the field of hearing devices are achieved through international research and the pooling of collective experience. Therefore, HEARRING members are committed to leading research in hearing device science, to advancing audiological procedures, and to developing and perfecting surgical techniques. (<https://www.hearring.com/>).

Why is this topic important?

Magnetic Resonance Imaging (MRI) is a non-invasive diagnostic procedure that uses strong magnetic fields to produce images of mainly joint injuries, intracranial tumours and lesions, and neurological diseases. This means that MRI scans are often performed to visualize the head or the spine. The strengths of the magnetic fields of MRI scanners range from 0.2 Tesla to 7.0 Tesla, with stronger magnets providing higher resolution images. Most radiology departments have 1.5 Tesla or 3.0 Tesla MRI scanners.

Hearing implant users are likely to have at least one MRI during their lifetime. Cochlear implant users, in particular, are often implanted at a very young age. Therefore, they might be affected by additional health complications associated with hearing loss, such as diseases of the inner ear, at some point in their life.

It is important to know that MRI interacts with the implant magnet and thus can cause complications, including artefacts or distortions on the MRI image, dislocation of the implant magnet, demagnetization, an increase in temperature around the implant, or pain.

In the past, the hearing implants would often have to be surgically removed before the

MRI; however, now, there are MRI-conditional cochlear implants. This means that they can be worn when having an MRI (up to a strength of 3.0 Tesla) without the need for magnet removal. In most patients, a protective head bandage is used when the magnet is not removed before the MRI. A survey by the HEARRING group clearly demonstrated MRI safety of such implants with a low number of complications. Implantation of a hearing implant with a removable magnet is recommended for individuals who require regular MRI scans of the head region. But even without magnet removal, most head MRI scans in cochlear implant users are diagnostically useful.

Our goal for the future is to make radiological departments aware of the different types of hearing implants with regard to the MRI-compatibility of hearing implants.

For further details, please see: Van de Heyning P, Mertens G, Topsakal V, et al. 2021. Two-phase survey on the frequency of use and safety of MRI for hearing implant recipients. Eur Arch Otolaryngol. 278(11):4225-33.

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[WORLD NEWS - KYRGYZSTAN - Report on the seminar on the topic “Rehabilitation of children with a cochlear implant” in Osh, Kyrgyzstan](#)



We were able to carry out this seminar in February 2022 due to the framework of the grant program “Cochlear Implantation and Long-Term Support of Deaf Children” received by the Lehnhardt Foundation from the German Society for International Cooperation (GIZ) for specialists in Kyrgyzstan. Our purpose was to raise awareness of specialists and parents about the rehabilitation of children with cochlear implants.

The seminar was held in the building of the Department of Social Development of Osh city. By the way, the hall in which the seminar was held was equipped according to the GIZ project. Specialists from Osh - Myrzakarimova Nurkyz and Ergasheva Zebenisso helped us a lot with the organization of the hall, in my opinion, they are very interested in organizing rehabilitation in their region. 40 participants were registered at the seminar, including 14 parents and 26 specialists (ENT-doctors, surdologists, speech therapists, speech pathologists, psychologists). I want to note that we were very pleasantly surprised, the specialists came in advance and were interested. Many specialists and parents came from other cities (Jalal-Abad, Batken, Uzgen, Nookat).

To the participants demo sets of cochlear implants (MED-EL and Cochlear firms) were shown, which made it possible to show visually and practically how the cochlear implant system works. Before the start, we distributed information materials to the participants about the "PORA!" webinars from Lehnhardt Akademie and about the work of the IAHRs (International Association of Hearing Rehabilitation Specialists).

In the first half of the first day, I explained the theoretical part about the device, the work and capabilities of the CI, about preparing for the surgery and what to do before and after fitting, how to fit the speech processor. After the break, Larisa Kovaleva spoke about the stages of auditory-speech development, how important it is to develop hearing first of all, the importance of interaction of rehabilitation specialists with parents, about the principles of working with parents. We were very lucky that one of the mothers had a daughter, a candidate for CI, with her the importance of classes before the CI was shown, we showed that a deaf child also has reactions to sound. At the end of the first day, we gave homework, dividing the participants into two teams.

On the second day, we decided to involve the participants of the seminar even more in practical activities. We started the second day of the seminar by checking the homework and physical exercises that charged everyone with a good mood and prepared them for work. In the first half of the day, we spoke about the rules of behaviour and communication with a child with CI, introduced 7 blocks of games aimed at developing auditory perception at the initial stage of rehabilitation. We conducted a practical part for each block of games, after which there was a discussion. Immediately after the break, there was an online meeting with Yvonne Seebens (Head of the therapy department CIC Rhein-Main, Germany). In the conversation, Yvonne especially noted the relevance of the natural auditory behaviour of parents and the child, spoke about the need for emotional interaction with the child. After Yvonne's speech, we continued the practical part of our seminar. A lot of methodological and practical literature on CI was provided to everyone in electronic form.

In the final part of the seminar, there were many questions from both, specialists and parents, which turned into a discussion about the way of the organization of rehabilitation in the regions of the country.

The key point was the proposal from specialists to hold detailed seminars (practical) in the regions.

In conclusion, certificates were issued to the participants.

We would like to note the activity and interest of the participants in the work carried out by us. We express our gratitude to you on behalf of parents, specialists and us personally for organizing such a large-scale seminar.

Anastasia Naimanova and Larisa Kovaleva from Bishkek, Kyrgyzstan

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WORLD NEWS - RUSSIA - Laying the foundations for independent speech



I go into the kindergarten group and see: an unfamiliar child is standing in the doorway, holding the hands of his parents. He has a hearing implant, and I understand that this is my new pupil. With interest, smiling, Vova looked at me and went to the group where the hearing kids played. So easily began the first day in the mass kindergarten of a boy who was different from his peers from the first day of his life.

Vova Krivobokov is 4.5 years old. He has a cochlear implant on one side, signs of cerebral palsy, a respiratory stoma and wears glasses. In his short life, the boy had to undergo many surgeries to ensure his viability. Only his parents can say what challenges he had to undergo and how risky it was. And Vova is definitely lucky with his parents! They did not give up when it turned out the child has multiple malformations, and Vova's two older sisters help them and play with the boy. Without despair and with faith in the future, they do their best today. It's been for 2 months now, that this child goes to the regular Moscow kindergarten, along with his hearing peers.

For more than 40 years, our teaching facility has been providing correctional assistance to children with hearing impairment. Special education teachers of preschool and school departments work according to the Dr. Emilia Leonhard proprietary methodology. Every day for 2-3 hours Vova is among his hearing peers. Every day this child has the opportunity to receive correctional assistance. After a while, I caught myself thinking that I don't pay any attention to all the limitations in the development of Vova when he is among children.

He draws, plays, runs and moves to the music in the same way, and only in silence the whistling sound of his breathing tube attracts attention. When he is with the children, you even forget that Vova cannot hear like healthy peers. With the support of the German Lehnhardt Foundation, the "Hearts to Children" organization and the **Moscow Pomogi Foundation**, the doctors of the AMEOS clinic in Germany gave Vova a missing auditory function, which became the physiological basis of listening and hearing, and provided the boy with the ability to hear.

In August 2020, Vova underwent a cochlear implantation on the right side. After such a surgery people hear a sound stimulus, but they cannot learn to hear speech, which means to understand it, on his own. This is a long and difficult path. This needs to be taught specifically.

When he started in the kindergarten, Vova had already formed a reaction to sound - he learned to understand that there is a sound. And that's already a lot. This is an achievement, keeping in mind that Vova did not react at all to sound stimuli before the surgery, and they tried to teach him the first sign language gestures. In kindergarten, daily classes began to teach him meaningful listening. At the initial stage, Vova listened only to babbling forms of words, correlating what he heard with a toy. He was taught without the

help of gestures and without dactylology, using only the oral form of speech.

I would especially like to note that the teacher addresses a child of this level of speech development with simple words that he can understand: here, there, then, let's go, yes, no, give, okay. In no case should a stream of non-adapted adult speech flow to the child. A child who has just been "included in hearing" does not understand anything in such detailed statements of the teacher. Without understanding what he has heard, the child cannot form a readiness to reproduce the proposed vocabulary in his own speech. This is a very important moment in the development of speech hearing and speech memory of a deaf child. A person is ready to actively use the words whose meaning he understands.

Today, Vova already understands some full words: mom, give, dad, fish, aunt, fell, dog, sleeps ... - and sometimes tries to pronounce them. He vocalizes more and more actively, can repeat the structure of a familiar two-syllable word. Understanding speech in a child with hearing impairment is not formed spontaneously over a given period of time. Word by word when the child understands and actively uses them, the words are accumulated, remembered, combined into a phrase. But for Vova, this is still a sky-high distance. When he was deaf, he was silent for a long time. His articulation capabilities must be developed with the help of massage and exercises. But the most important thing is: Vova should not be afraid to sound, he should want to sound like all the people around him. Adults are happy with any independent correlated babble, and any outline of a word. The way goes from the understanding of someone else's speech to active independent speaking. The beginning is made! There is a long way ahead!

The physiological ability to hear, the speech environment, the child's own cognitive activity, and a loving and supportive family, plus daily corrective assistance - these are the "bricks" that will make a baseline in the development of the child's independent speech. Go, Vova, go!

Anna Peksheva, a special education teacher in the 224 school in Moscow

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[WORLD NEWS - UK - British Cochlear Implant Group \(BCIG\)](#)



Launch of new information leaflet

The importance for people with Cochlear implants and Radiographers both being fully aware of possible difficulties that could happen during an MRI scan has long been recognised by BCIG. A new information leaflet has now been produced which will be available on the BCIG website shortly. Head splinting and bandaging is fully explained and the leaflet seeks to reassure patients about the procedure.

For the benefit of radiologists, a series of training videos has been produced in conjunction with Simon Lloyd of Manchester University. These will also be made available via the BCIG website.

People with a cochlear implant having an MRI scan should always get advice from the individual cochlear implant manufacturers – [please see our website for details](#).

Revised Quality Standards

The Special Interest Group for the revision of the Quality Standards is putting the final touches to the document. Members of the group, including Dan Jiang and Louise Craddock, will be presenting at the BCIG Conference in Cardiff. Each sub-section – surgery, audiology, rehab – has been revised to incorporate new, evidence-based practices brought about, in part, by the pandemic. Thank you to all who have contributed!

More badges have arrived!

Our badges have proved very popular - if you didn't manage to bag yourself a badge or two last time, we have just taken delivery of some more. Please contact Laura to request your free badge info@bcig.org.uk

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WORLD NEWS - UK - Auditory Verbal UK (AVUK)



Photos: David with his mum, Irina Tiselita (in the left photo), and Sophie Williams (in the centre photo)

CIICA's First Anniversary

AVUK is delighted to have been part of CIICA's first year and anniversary conversations around the impact of the pandemic.

We look forward to continuing working with colleagues across the globe including how we can support those affected by the conflict in Ukraine.

#HearUsNow – World Hearing Day

With children at risk of falling further behind as a result of the COVID-19 pandemic, AVUK are calling on the Government to invest in early and effective support for deaf children in the UK.

AVUK launched the #HearUsNow campaign on World Hearing Day (3rd March), asking the Government to make an investment of £21.5m over the next 10 years, so that they can provide a sound future for deaf children and unlock an economic benefit of £152m. This will enable all families who want their child to learn to listen and talk, to be able to access Auditory Verbal therapy through publicly funded services, close to where they live. [Find out more](#).

Perspectives on:

World Hearing Day also saw the launch of a new series of video podcasts which will explore the theme of hearing.

The [first episode](#) saw AVUK graduate 14-year-old Ava Pearson interview Gwen Carr, who is an Early Hearing Detection and Intervention consultant and a leading advocate for Family-centred intervention.

International Cochlear Implant Day

International Cochlear Implant Day gave AVUK an opportunity to celebrate the achievements of children with Cochlear Implants. We shared [Sam's hearing journey](#) and his explanation of how cochlear implants help him.

We also shared and stories of support including two fundraisers taking on a half marathon challenge for the charity. This includes [Irina Tiselita](#) whose son David graduated from AVUK eight years ago and [Sophie Williams](#), a speech and language therapist who has just started the AVUK [Foundation](#) course.

Impact Report

We are pleased to announce the launch of our latest Impact report. The report, which covers the period from August 2020-July 2021 shows how we've supported families through the pandemic and how we're transforming access to services. We also highlight AVUKs outcomes and our plans to build for the future.

[Anita Grover, CEO of AVUK](#) says *"The past year has been a challenging one; for the children we work with, their families and for AVUK. Despite the unprecedented difficulties that we have all faced, I am delighted that we have been able to continue to provide exceptional support for our families and expand our efforts to transform services for deaf children in the UK. As AVUK looks to the future, we remain passionately committed to raising expectations for deaf children through our services, our communications and our research. We simply could not do what we do without the support we receive from individuals, organisations, charitable trusts and foundations and we look forward to continuing to work in partnership with our supporters to achieve our vision."*

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[WORLD NEWS - UK - British Association of Teachers of the Deaf \(BATOD\)](#)



Deaf**Kidz**
INTERNATIONAL

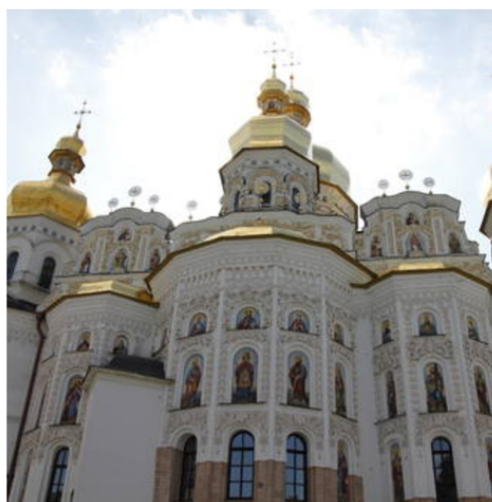
DeafKidz International are delighted to announce a new partnership with the [British Association of Teachers of the Deaf \(BATOD\)](#) on their “Audiology Refreshers Project.”

Funded by the William Demant Foundation, this project aims to update a resource for Teachers of the Deaf, students and other professionals working with deaf children and young people, to reflect current practice and to provide an online, open-source resource to refresh basic audiological knowledge and practices. DKI will co-ordinate the project, working in collaboration with BATOD, the British Society of Audiology, as a lead partner and, other key partners in audiology, education for deaf children, and assistive technology within the UK.

We will keep you updated on our progress on [BATOD](#) and [DKI](#) websites.

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[WORLD NEWS - UKRAINE - Hotline - immediate support for parents when their baby did not pass neonatal hearing screening](#)



In June 2021 the Lehnhardt Foundation submitted its third project to the GIZ (German Agency for International Cooperation): “Implementation of New-born Hearing Screening in 4 clinics & professional parents counselling via Hotline”.

This project is under the umbrella of “Clinic Partnership” and our partner is the Medical Centre for hearing rehabilitation AURORA, a non-governmental health institution, licensed and accredited in the highest category by the Ukrainian Ministry of Health in Kyiv. It was established in the year 1991 and since then – over 30 years – more than 70,000 patients of all ages were treated there.

There are four ENT doctors, five medical nurses, four speech therapists, two engineers and administrative staff working in AURORA.

As early as in the year 2000 objective neonatal hearing screening using OAE and ABR was introduced by them in the region of Kyiv. And, since then, they offer in-depth diagnostics, early hearing intervention and (re)habilitation following protocols developed in the US, Europe and Australia.

The Lehnhardt Foundation and MC AURORA have been in close contact since 2019 and we together analysed the current situation concerning NHS, diagnostics, “Loss to follow-up”, provision of hearing aids / cochlear implants and (re)habilitation in Ukraine.

Significant shortcomings were found at all stages of the process: there are no uniform screening protocols, there is no central data collection and evaluation. The conspicuous ‘screened’ new-borns cannot be traced and the so-called “loss-to-follow-up” is therefore far too high. The provision of hearing aids or CI as well as (re)habilitation is not satisfactory.

The current process indicates that inclusion is still a goal far away.

In order not to unsettle the parents of children with normal hearing and in order to be able to bring hearing-impaired children to therapy as soon as possible, the conspicuous results after the screening must be clarified as soon as possible. The reactions of parents to what sounds nearly as a verdict - "Your child most probably has a serious hearing impairment" - can be very different.

The vast majority of parents fall into a stage of emotional shock. They suffer a psychic trauma.

"DEAF" is all they hear – "This is not the child we wanted". "Will my child ever find friends / a partner in life?" " ..after that – the world cannot ever be the same", "the whole world collapsed/fell into ruins".

Some parents fall into the state of depression and become lethargic. They stop talking to their baby "she/he cannot hear me anyhow". They stop communicating with their child which means stop eye contact and do not seek physical nearness. The consequences are detrimental for the child.

Some parents fall into a state of denial. "It can't be," "Everyone in our families hears well," "It'll grow out" - and they are looking for "experts" who will reinforce their opinion, seeking "miraculous" treatment. Early intervention, which would be necessary, does not take place and valuable time is lost.

Unfortunately, some parents blame each other or blame some external circumstances for their child's deficit. "Why has it happened to me?", "What had we done so wrong that we have been punished that way?". They escalate into a state of aggression that makes reasonable action almost impossible.

There are also parents who become hyperactive in a state of panic, following unprofessional advice on the Internet and thus ultimately being counterproductive for the child.

With these reactions to the announcement of a possible significant hearing impairment in the new-born, parents all over the world are similar. Basically, all have to go through a period of mourning.

What do they need to get into the difficult process of constructive adaptation to the new situation? How can they be supported to ask the question "How can we help our child?" "What depends on me?"

In our project supported by GIZ we want to address the first moments in these processes.

The Medical Centre AURORA will serve as a reference for the submitted 'Hotline' project: Neonatal hearing screening will be performed in 4 maternity clinics in the region of Kiev. They will be equipped with appropriate screening devices in order to carry out NHS according to uniform protocols - a two-tier NHS (OAE and ABR) with the lowest possible referral rate.

Furthermore, these clinics should be able to offer initial paediatric audiological diagnostics. The paediatric audiology department at MC Aurora serves as a reference clinic.

Immediately after a positive result of the NHS ("no pass") parents are directed to a hotline where well-trained professionals will give them detailed advice on what further steps are required, what options are available, and whom to contact.

Until recently we were confident that our multi-national/multilingual team will communicate effectively Online by Videoconferencing, Skype, WhatsApp and email. We were hoping that the COVID 19 situation would soon allow for personal visits. The medium-term goal was for AURORA to become the supervisor for 10 clinics, paving the way for a nationwide

NHS.

Since February 24th the world has changed. Needless to say, that we are seriously affected. However, we are far from giving up. Additionally strengthened by the promise of further financial resources from the GIZ, we will change the focus of our short-term activities and at the same time intensify them. Our long-term goals have remained the same. The word hotline has taken on a different meaning at the moment. It serves to strengthen the communication of our international team.

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[WORLD NEWS - USA - Tuesday Talks: American Cochlear Implant Alliance Cochlear Implant Consumer Advocacy Network Members Lead the Way](#)



Kick off 2022 with our engaging speaker series highlighting important upcoming events and developments in cochlear implants and hearing loss. The talks will be introduced by Cochlear Implant Consumer Advocacy Network (CI CAN) members who will also moderate the Q&A. Presentations will take place virtually over the lunch hour from 12-1PM US Eastern Standard Time (EST) with an opportunity for attendees to interact with each presenter. All sessions are free to attend and will be captioned and recorded for viewing after the series has ended.

[Click here to register](#)

[Click here for flyer](#)

- **Tuesday, January 18th – Why We Need to Talk about Late Onset Hearing Loss**
[Valerie James Abbott, Author and Advocate](#)
- **Tuesday, February 15th - Understanding Your Child's CI Programming Session**
Terry Zwolan PhD, Director of Audiology at [Hearing First](#)

• **Tuesday, March 15th – Rally Caps and the Importance of CI Representation**

[Jodi Michelle Cutler, Author and Filmmaker](#)

• **Tuesday, April 19th – Understanding an Adult's CI Programming Session**

Meredith Holcomb AuD, Associate Professor; Director, Hearing Implant Program;
Associate Professor, University of Miami Miller School of Medicine

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[WORLD NEWS - USA - Cochlear Implant Rehabilitation for Adults by Naama Tsach PhD, Speech-Language Pathologist and Educational Audiologist](#)



Naama's blog explores a range of issues intended to support adult CI recipients including emotional matters, challenges, and tools and approaches that can enhance listening and understanding. It also addresses understanding speech, identifying sounds in the environment, appreciating music, deciphering recorded speech, and conducting telephone conversations.

[Read her latest posts here](#)

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[RELATED CONGRESS - British Cochlear Implant Group \(BCIG\) CONFERENCE - UK](#)



[\(Photo: Venue in Cardiff\)](#)

Full steam ahead for Face-2-Face conference 26th – 27th April!

The programme is announced, the hotels are ready – have you registered yet for the BCIG Conference in Cardiff on 26th and 27th April?

[Registration available here.](#)

The International Faculty includes: **Doris-Eva Bamiou**, UCL Ear Institute, UK; **Cate Calder**, Cued Speech, UK; **Marco Caversaccio**, University of Bern, Switzerland; Enrique A. Lopez-Poveda, University of Salamanca, Spain; **Matthew Winn**, University of Minnesota, USA.

The Graham Fraser Memorial Lecture will be given by **Catherine Birman**, from the Sydney Cochlear Implant Centre, Australia.

It's going to be great to meet up with everyone again.....

This year's Annual Dinner will be held in the wonderful Cardiff National Museum and Art Gallery. This impressive building houses world class art and natural history and is situated next door to Cardiff City Hall – the venue for the conference.

Croeso cynnes i Gymru! - A warm welcome awaits you in Wales!

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[RELATED CONGRESS - American Cochlear Implant Alliance CI2022 DC Conference on Emerging Issues: Opening Speaker Lou Ferrigno - USA](#)



We are pleased to announce that Lou Ferrigno, popularly known as *The Incredible Hulk*, will help us open the upcoming CI conference. *The Incredible Hulk* is a trademark of Marvel Characters, Inc. Lou is an American actor, fitness trainer, and inspiration to several generations of film and TV fans. He recently received a cochlear implant. He is candid about the challenges he faced given his childhood hearing loss and how he overcame them. [Read More here](#)

In February 2021, Lou, received a cochlear implant. We were fortunate enough to interview him. ACI Alliance Executive Director Donna Sorkin and Lou discuss his lifelong hearing loss and why he went forward with a cochlear implant at age 69. [Watch the entire interview here](#)

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[RELATED CONGRESS - National Cochlear Implant Users' Association - Summer Meeting and AGM - UK](#)



The 2022 Summer Meeting and AGM of the [National Cochlear Implant User' Association](#) will be held in London on Saturday 11 June. The venue will be [Birkbeck College](#), Room B04, Birkbeck University of London, Malet Street, Bloomsbury, London, WC1E 7HX.

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[RELATED CONGRESS - HeAL 2022 - Hearing Across the Lifespan - Italy](#)



Cernobbio, June 16-18, 2022 (FACE-TO-FACE)

Our next [HeAL Conference](#) (live) will be held on June 16-18, 2022 at our historic venue, the gorgeous Villa Erba Conference Center, on Lake Como in Cernobbio.

In the 2020 Conference that had to be cancelled a few months before the start, the quality of the approximately 320 communications (oral and poster), divided into four parallel sessions, would have been among the highest ever in the history of the so-called Como Conferences, also considering the very interesting special sessions and mini-symposia that had been scheduled.

In [HeAL 2022](#) the Program promises to be just as exciting and fulfilling as in the previous meetings if we assume that the submissions scheduled for the 2020 meeting will be confirmed, while we expect many other quality submissions to have been received by the deadline of the Call for Abstracts (October 31st, 2021).

The Program will be complemented by comprehensive exhibit. Ample time will be allowed for all participants to visit the exhibits and speak with exhibit representatives.

Most promising, and not to be missed, should be also the presentations included in the New Technologies Area.

We sincerely hope you will be able to join us for another exciting conference in Cernobbio which is ready to host our conference once again, with all its charm of a cozy, little frequented and safe town on the Lake Como!

Ferdi Grandori (Chair)

CNR-IEIIT

Institute of Electronics, Information Engineering and Telecommunication

Dept. of Electronics, Information and Bioengineering, Polytechnic of Milan, Italy

Sophia E. Kramer, PhD

at the Amsterdam UMC – location VU University Medical Center in Amsterdam,

The Netherlands

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[RELATED CONGRESS - BATOD National Conference 2022 'Positive Mental Health and Well-being for all' - UK](#)



BATOD is in the process of planning our next national training event, which (hopefully) will be a physical conference! Please save the date:

- 24th September 2022
- Frank Barnes School for the Deaf, London
- Theme: 'Positive Mental Health and Well-being for all'

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[RELATED CONGRESS - IFOS World Congress in 2023 - Dubai](#)



As a result of the ongoing global COVID-19 pandemic, the Canadian Society of Otolaryngology - Head and Neck Surgery made the difficult decision to cancel the planned June 2022 meeting.

IFOS 2022 Vancouver President, Brian Westerberg, commented:

"The pandemic has already caused, and continues to cause, countless challenges with respect to organising a high-calibre, in-person meeting here in Vancouver. The numerous unknowns of what lies ahead have made it impossible for us to move forward in arranging the type of meeting we originally started planning in 2017. As a result, we have had to make the unfortunate decision of cancelling the meeting entirely."

The IFOS Executive made the decision to move the meeting to a new location and it will now be hosted in Dubai on 16 - 21 January 2023. Please keep an eye out for further information from **IFOS** regarding the conference.

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[RELATED CONGRESS - European Symposium on Pediatric Cochlear Implantation - The Netherlands](#)

ESPCI
CROSSING BRIDGES

European symposium on
pediatric cochlear implantation

ROTTERDAM, MAY 31ST - JUNE 3RD

www.espci2023.org

It is with great pleasure and enthusiasm that, on behalf of the Cochlear Implant centers of the Radboud UMC in Nijmegen and Erasmus MC Sophia Children's Hospital in Rotterdam, we invite you to attend the European Symposium on Pediatric Cochlear Implantation in Rotterdam, The Netherlands in 2023.

Yours sincerely, on behalf of the CI Centers at Radboud UMC and Erasmus MC.

Prof Dr Emmanuel Mylanus

Dr Ir Jantien Vroegop

Dr Ronald Pennings

Dr Marc van der Schroeff

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[RELATED CONGRESS - 17th International Conference on Cochlear Implants and other Implantable Technologies - Canary Islands, Spain](#)



This is to inform you that considering that **IFOS World Congress** will take place in Dubai in January 2023, the Organising Committee of the **17th International Conference on Cochlear Implants and other Implantable Technologies** has decided to change the dates of the event as follows: **21 – 24 February, 2024**.

We have decided to move the event to the following venue and city: **Auditorio Alfredo Kraus – Las Palmas de Gran Canaria, Canary Islands, Spain**.

We are currently preparing a new web page for the event, which will be available soon at:
www.ci2024spain.com

Our Technical Secretariat will be available on the following mail: info@ci2024spain.com

We remain firmly committed, from now on, to organize a major scientific event in 2024 creating a worthwhile framework for the CI and other implantable technologies community across the globe, with meaningful contributions from prestigious international professionals.

Regards,

Angel Ramos and Manuel Manrique
Co-Chairmen CI2024

info@ci2024spain.com

Telephone: (0034) 928 27 30 27

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ADVANCED BIONICS - Introducing the HearingSuccess Portal



HearingSuccess

Connect to the sounds of life

HearingSuccess.com



Practice, learn and connect.

Are you considering a cochlear implant for your child or a loved one? Getting cochlear implants is the first step to connecting to a life filled with sound when hearing aids are no longer beneficial. However, not all the challenges of hearing loss disappear after getting cochlear implants. Your brain needs to adapt to this new way of hearing, so it is important to practice.

What can you do to help yourself, a loved one or your child succeed with cochlear implants? Set goals, learn strategies, practice listening and connect with others to support everyday communication.

Advanced Bionics and Phonak are introducing auditory skills training via the HearingSuccess portal. Discover activities, information and communities to support you. All the resources you will find at HearingSuccess.com are available at no cost.

What are you waiting for? Get started today!

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ADVANCED BIONICS - Hearing Loss Jargon: What They Said and What They Mean



If words like pinna, cochlea and sensorineural aren't part of your daily language – you aren't alone. The amount of medical vocabulary surrounding hearing can make your head spin. Add in a hearing loss, and you aren't sure if your audiologist said bilateral, binaural, or bimodal. There are so many specialized terms used around hearing loss and hearing technology that it might become confusing.

On our blog, **CONNECTIONS**, we have put together an article that will help clarify some of these terms and help you find the right solution for your hearing loss. Perhaps, the next time you speak with your hearing care professional, you will feel more empowered to discuss how these terms apply to you or your loved ones, and what is the best solution for your hearing loss.

Make sure to visit our blog regularly. Explore it to find the powerful stories CI experts, CI recipients, or parents of children with CIs are sharing with us about their hearing journey and other helpful articles on hearing loss and cochlear implant technology.

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MED-EL - Wearing options for children with glasses and hearing implants



Thanks to a range of CI audio processors and fixation accessories specially designed for children, parents can choose a configuration that's ideal for your child. A popular choice is a behind the ear option such as the **SONNET 2**. As parents well know, wearing both glasses and a behind the ear audio processor can bring some unique challenges when encouraging little ones to keep both devices on. This can be particularly frustrating if you're trying to increase the amount of time your child listens with their audio processor each day.

To help you with this, we've collected some recommendations to guide you when choosing glasses frames as well as some tips about wearing options for children of different ages.

For routine eye care, consider consulting a pediatric optometrist - an eye doctor who provides comprehensive eye exams and regularly fits glasses for young children. A child-friendly professional can help minimize the stress of future eye exams and offer eyewear options that are durable and comfortable for little ears.

When it comes to your child's frames, look for eyewear that suits active play, and the occasional fall or tumble granting a secure but comfortable fit. For maximum comfort with an audio processor, ask your optometrist about frames that are:

- Lightweight
- Made of a soft highly flexible material (e.g., plastic, silicone)
- Have no metal parts
- Include an adjustable or removable head strap

Before you commit to buying glasses, think about how your child could wear their frames. Comfort is a must for long-time use and only you and your child can decide which wearing options work best for your daily routine.

Visit our Blog to learn more! We've shared some more top tips for you to consider when evaluating glasses for your little one.

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MED-EL - Be part of Virtual Voices & Band!



Enjoying music or even playing music with a cochlear implant is a complex task, but one that more and more CI users master - thanks to sophisticated technology, excellent rehab material for musical training and, of course, their perseverance in practicing.

MED-EL wants to show the world how much joy music brings hearing implant users and

how well many of them are able to perform music. Join us and be part of this once-in-a-lifetime virtual music experience! “

Virtual Voices & Band” is a global event where hearing implant users from all over the world - and of all brands - will perform a song together! It does not matter what instrument you play or how well you sing—anyone can be part of Virtual Voices & Band.

The result of this global music project will be showcased online this autumn. Want to know more?

Register now and get more information and updates via email.

Link to Form (EN only): <https://bit.ly/36KQtc6>

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OTICON MEDICAL - Notification of Expected Return to Market



Oticon Medical Neuro Zti cochlear implant

You may recently have learned that Oticon Medical voluntarily withdrew the Neuro Zti cochlear implant from circulation. Oticon Medical took this action because we had identified a small number of devices that were not completely air- and liquid-tight. We withdrew all non-implanted devices from hospitals and clinics around the world while we investigated the problem. The number of faulty devices has remained low at 2%. There have been no safety events reported with these devices.

All existing Neuro Zti users are advised to continue to use their device as normal since the prevalence of the problem was very low and there were no reports of safety events. If you as a user, or your child, experience issues in sound quality, this is most likely associated with the external sound processor. The implants at fault have been identified by an unexplained loss of communication between the sound processor where normal troubleshooting procedures (checking the sound processor, the cable, the antenna, and the battery, one piece at a time) are ineffective in solving the problem. In this instance users should visit their hearing clinic for further checks.

Oticon Medical are happy to say that we identified the cause of the problem as relating to small irregularities in the production process. The problem did not originate in the design of the implant. We have been able to correct these irregularities and are implementing additional, stringent production and testing processes to prevent similar issues from occurring again.

We will submit the necessary documentation to the relevant health authorities and expect the

Neuro Zti to be back in CI clinics and hospitals from the third quarter this year.

We hope with this notification, that you will feel confident as a Neuro System user. The reliability of Neuro Zti implant is among the best on the market, and whilst this issue has

dented the reliability record slightly, we can expect the Neuro Zti to continue to be one of the most reliable cochlear implants available in the future.

If you have further concerns or questions please contact your local Oticon Medical representative or the local Oticon Medical Customer Service where you will find someone eager to help you. Contact details can be found on the webpage [Oticonmedical](#) and on your patient card.

Oticon Medical has more than 25 years of cochlear implant experience and is an integral part of one of the world's largest hearing healthcare groups, Demant, who've been committed to hearing health for over a century. We are truly sorry for any concern and disruption we may have caused you or your family. We would like to reassure you that, at [Oticon Medical](#), we are still fully committed to providing you with lifelong support.

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[OTICON MEDICAL and the commitment to R&D: How we support our CI users in their everyday life](#)



Recently it was International Cochlear Implant Day and we couldn't miss the opportunity to celebrate all the CI users from around the world. At Oticon Medical, the 25th of February has several meanings. It's not only a day to create awareness around the cochlear implant solution for those seeking to overcome a hearing loss; it is also an annual event aimed at strengthening a vast community of worldwide CI users, reminding them all that they are part of a bigger community who will support them in everyday life's up and downs.

How do we, at Oticon Medical, provide our users with such support?

Firstly, we create and spread awareness on our most up-to-date solutions that can help facilitate the daily challenges of a CI user, from new products and accessories to supportive customer assistance.

Secondly, we strive to push the boundaries of technology to offer increasingly innovative and customized solutions to all our users. The voluntary, temporary withdrawal of the Neuro Zti implant in October 2021 did not stop us in this quest. More than ever, we are committed to investing in the research and development of innovative hearing solutions. Our purpose is to provide our users with better hearing performance and improved quality of life. We do that by collaborating closely with basic and clinical researchers worldwide. We support hearing health research with advanced tools that lay the groundwork for the development of the next generation hearing implants; tools that aim at investigating the real-life challenges and daily pain-points of CI users, so that we can collect precious insights on user behavior and the relative performance of CI therapy in real-life situations.

We do all that because for us sound does matter!

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