

#### EURO-CIU NEWSLETTER - SEPTEMBER 2023 Download PDF version

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Message from the President



This will be one of my last messages as president. My mandate is almost over and it is time to take stock of this turbulent time, which I hope has been positive for EURO-CIU.

We have gone through really difficult years that with effort and dedication we have managed to increase the value of the "Cochlear Implant" brand and, therefore, of EURO-CIU, creating awareness in Europe and around the world, even when we have defended "oralism", "integration", "accessibility" and "design for all"; in addition to collaborating with global projection with the WHO, CIICA, EHIMA, several universities and other organizations as well of course, all commercial brands of cochlear implants.

The COVID, this misfortune that struck the world, deprived us of the celebrations we deserved for our 25th anniversary; but we were able to

adapt and re-emerge thanks to new technologies, holding more meetings that connect us even without the human warmth of being in person.

I am pleased to confirm that EURO-CIU has achieved a level of respectability and visibility never before reached thanks to the team that has surrounded and supported me to walk in this direction. We have shown the European institutions (European Parliament & Commission and European Forum of Disabilities) and the World Health Organisation that deafness has different realities. Hearing loss is not synonymous of silence, but on the contrary, we are a powerful collective raising our voice, showing our listening.

After years of work and advocacy, the disability card has finally been presented by the European Commission, as you can see in this newsletter, and we will be able to enjoy it as a collective.

Our path does not end with me and everyone's participation and involvement is very important.

I remind you that in the next General Assembly there will be elections and I invite you all, but especially cochlear implant users to run for the vacancies on the Board (Presidency, 1st Vice Presidency and Treasurer).

For all this, I am waiting for you at the EURO-CIU Workshop Valencia, the next 3rd and 4th of November 2023, to develop our collaboration, focusing specifically on the following topics:

- 1. Synergies between Cochlear Implant NGO's and the Cochlear Implant Industry.
- 2. How to approach the Health/Disability Commission in your country and the European Parliament.
- 3. Future Paths & Joint Actions from EURO-CIU Members.

Working together so that the conclusions of these workshops will help to build a future full of sounds for our organizations, our members and our families. I look forward to seeing you!

#### Teresa Amat (President, EURO-CIU)

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#### Message from the Newsletter Editor



I understand that, meteorologically, it's now Autumn - so I hope that you've all had a good summer!

Many thanks for your contributions - it's good to hear from you all. We are also grateful to the cochlear implant companies for keeping us up to date.

As always, there are a lot of articles and photographs in this edition.

Please feel free to forward this Newsletter to Members of Parliament, Members of the European 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! If anyone you know would like to receive their own copy of this newsletter, just send me their email address.

The next edition will be due in December, so please let me have your articles and jpg photos by Monday 4 December 2023. Just e-mail them to me at newsletter@eurociu.eu

It just leaves me to wish you good health.

#### Brian Archbold (Editor)

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EURO-CIU – Annual General Assembly and Board Elections



On the 4th November 2023 in Valencia, EURO-CIU will hold their Annual General Assembly and Board Elections.

President, 1st Vice President and Treasurer positions are available for election.

All member associations are invited to present their candidates before 15th October 2023.

Please send your proposals to our secretary: pieterbolle@gmail.com

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EURO-CIU Workshop and General Assembly 2023 Valencia: Building Accessible Communication Bridges. Cochlear Implant Users Learning From One Another



Please make a note in your diaries that our EURO-CIU Workshop and General Assembly will take place in the beautiful Spanish city of Valencia on 3 & 4 November 2023.

The Workshop will be held at Senator Parque Central Hotel, where you will be able to stay during those days.

Every detail concerning accommodation prices and type of rooms as well as meals and other important information can be found on the registration form. Every person coming to the event must complete it. Click here to open the form

Remember that all EURO-CIU members are invited.

If you need further information or if you have any questions, please contact us through eurociu@implantecoclear.org

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CIICA – Cochlear implants and deafness: a global case-study to increase policy awareness and action on an underresourced health issue.



A study of the development of CIICA (Cochlear Implant International Community of Action) as an international health network has been published by the International Journal of Audiology (IJA) at https://www.tandfonline.com/doi/full/10.1080/14992027.2023.2231634 (Paywall).

The study charts the development of CIICA and the research that informed that development. It has also drawn on academic studies of health networks for specific lessons for the hearing loss and deafness sector and more general principles that can be applied to health networks. Global Health Networks have grown massively over the last few decades in response to pressing health problems that cannot always be tackled on simply a national basis. Most conditions that incur high costs have provoked networks of advocates working to mitigate the impact, increase investment in research, and establish campaigns. Global health networks often work simultaneously across policy, knowledge creation, and advocacy. However, outside of the recent work by WHO there has been limited activity in global health networks and advocacy addressing profound hearing loss and deafness and the CI community. This has resulted in its relatively low visibility with policymakers compared to other health conditions.

CIICA aims to address this gap and bring together CI communities of advocates across the Globe to learn from each other and improve advocacy efforts in individual countries. It was established after research on stakeholders' views of current advocacy endeavours, opportunities and barriers, and the possible development of a global advocacy network to improve access to implantation and supporting services.

The insights from the study are that networks can be powerful in bringing people together for learning and action. Some of the key lessons were that:

- Successful patient or user engagement is a cornerstone of advocacy work for global networks to be successful.
- Harnessing effective leaders from the hearing loss community across different global networks is crucial.
- The severity of the issue and potential cost-effective solutions must be demonstrated and acted upon.

The paper notes that "Patient advocates in this field are the best conveyors of messages around the impact and severity of not addressing hearing loss and the benefits of taking action. From a public health perspective messaging about access to communication and the right to be able to hear resonates well within a human rights framework and offers an important basis for network development and building coalitions between groups with different circumstances"

For more information about CIICA and to join the network go to: https://ciicanet.org/

Brian Lamb, Public Policy Advisor, CIICA.AISBL

EURO-CIU is a founding member CIICA

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European Disability Forum (EDF) - People with Disabilities gathered at the European Parliament



Teresa Amat & Sari Hirvonen-Skarbö represented EURO-CIU

On May 23 over 700 disability rights advocates gathered in the hemicycle of the European Parliament in Brussels. The European Parliament and the European Disability Forum, 5th European Parliament of Persons with Disabilities created an opportunity to discuss the demands of the disability movement. The EDF Manifesto on the European Elections 2024 was agreed. The event was opened by the President of the European Parliament, Roberta Metsola and the President of the European Disability Forum, Yannis Vardakastanis. President Teresa Amat and Sari Hirvonen-Skarbö, members of EDF, represented EURO-CIU. Prior to this event was the AGM of EDF.

#### The panels and EDF Manifesto

Participants and panellists held discussions in panels throughout the day, divided into three topics:

- 1. free movement and full participation in society;
- $\label{eq:combating} \textbf{2. combating inequality, poverty, and social exclusion;}$
- 3. and working with international partners and other countries to create resilient societies.

There were dozens of speeches from several organizations, participants, and members of the Parliament.

It was mentioned that there is a need for disability-inclusive plans for emergency situations and humanitarian aid. These need to be cocreated with persons with disabilities. During the Covid-19 pandemic it became clear the need to improve rights for hearing accessibility. There should always be the possibility to provide assistive devices and accessible processes. Valerii Sushkevych, Member of National Assembly of Persons with Disabilities in Ukraine talked about the horrifying consequences during of the war. He underlined that children and persons with disabilities are more at risk. How the organizations of persons with disabilities act as "de-facto" humanitarian agencies and emergency responders while proactively advocating for disability rights. There is a lack of engagement with organizations of persons with disabilities, problems with evacuation and inaccessibility of bomb shelters.

The EDF Manifesto calls on EU political leaders to build an inclusive future for persons with disabilities in the EU. The Manifesto contains five points programmes. One aim is to guarantee the participation of persons with disabilities in political and public life. All persons have the right to vote and the right to stand as candidates. The overall level of accessibility of the EU institutions should be improved, including buildings and communications. The Manifesto calls to establish disability employment and skills guarantees for the Youth. It would ensure that persons with disabilities have equal access to mainstream education and employment opportunities.

Accessibility of communications should include the use of subtitling and other alternative communication systems. Embracing the accessibility needs to invest EU resources in increasing the knowledge and availability of speech to text, hearing assistive devices and national sign languages. The Manifesto also supports creating the new European Agency for accessibility.

#### Logistics

The EDF and EU Parliament made huge work for the logistics of 731 persons to attend to this event. It was recommended to arrive at the building early in the morning to go through the security points, that the event would start on time. During the day each country had the possibility to arrange meetings with their national MEPs. Finnish participants had an appointment to meet MEPs in the middle of the noisy vestibule.

The panel discussions were accessible. There were induction loops available, but first we had to find the right extensions to make them to work. There was real-time captioning in English and International sign interpretation on the screens. It was possible to choose captioning in 22 official EU languages, if you had own device with you. EURO-CIU wants to thank the staff of EDF and EU Parliament office for this work.

#### Sari Hirvonen-Skarbö

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European Commission – Questions and Answers on European Disability Card and European Parking Card for persons with disabilities



What challenges do persons with disabilities face when traveling across the EU?

Persons with disabilities encounter structural barriers and systemic inequalities that limit their full participation in society. Despite their equal right as EU citizens to move freely within the EU, their disability status is not always recognised across Member States. As a result, when persons with disabilities visit another Member State, they might not have access to the same special conditions and preferential treatment, such as free and/or priority access, reduced fees and personal assistance, or reserved parking spaces that are available to those with recognised disability status in that Member State. Such legal uncertainties may discourage or hinder persons with disabilities from traveling in the EU.

This situation creates legal uncertainty and potential additional costs for persons with disabilities. In addition, persons with disabilities may face other travel barriers due to high expenses for their specific needs. In 2020, 20.9% of persons with disabilities aged 16 and over were at risk of poverty in the EU, compared to 14.8% of those without disabilities. It thereby hinders them to exercise their free movement rights fully and effectively.

#### What are the main objectives of the proposal?

The proposed Directive's main objective is to ensure equal access to special conditions and preferential treatment for persons with disabilities during short-term stays in other Member States. It does so by:

- Introducing a standardised European Disability Card and improving the existing European Parking Card for persons with disabilities.
- Recognising the European Disability Card as proof of disability, granting access to special conditions and preferential treatment offered by private operators or public authorities.
- Providing holders of the European Parking Card for persons with disabilities with equal access to designated reserved parking spaces as well as other parking conditions and facilities.
- Making information available in accessible formats about how to obtain these cards and about the special conditions and preferential treatment offered for persons with disabilities.
- Reducing administrative burdens for persons with disabilities, private operators, and public authorities.

#### What does the European Disability Card cover?

The European Disability Card covers special conditions and preferential treatment from both public and private entities, including reduced fees, free and/or priority entry, personal assistance, support services (such as access to braille and audio guides), mobility aids, and more, offered by Member States to persons with disabilities residing there. It is designed to complement, rather than replace, national disability cards or certificates. Member States will continue to be competent for assessing disability status. The European Disability Card does not apply to employment or social security benefits nor social assistance.

#### Is the coverage of the European Disability Card equal in all Member States?

The European Disability Card will ensure mutual recognition of disability status in the EU. Its scope is the same across all Member States: it should provide the same access to special conditions and preferential treatment for persons with disabilities traveling to another Member State for short stays as offered by Member States to persons with disabilities residing there.

#### What improvements are proposed for the European Parking Card for persons with disabilities?

Although the current EU parking card for persons with disabilities should be recognised in all EU countries, evidence shows that users face uncertainties about their parking rights and experience limited recognition of the card when travelling to other Member States. This situation is exacerbated by differences in the card's format, design and implementation across the EU. Moreover, the Council Recommendation that established the European parking card model for persons with disabilities has not been updated to reflect developments in technology and digitalisation.

To address these issues, the Commission's proposal introduces an improved European Parking Card for persons with disabilities. It introduces a binding and standardised card model with security features to combat fraud and forgery. The new proposal also requires Member States to replace national as well as the previous European parking cards for persons with disabilities with the European Parking Card.

#### How can persons with disabilities apply for the European Disability Card and Parking Cards?

Each Member State must designate a competent authority to oversee the issuance, renewal, and withdrawal of both cards according to the respective national rules and practices. Member States will be required to provide information on the application and procedure in accessible formats, including digital.

National public authorities will be responsible for issuing, implementing and ensuring the common recognition of both the European Disability Card and the European Parking Card for persons with disabilities. Member States are required to take steps to prevent forgery or fraud related to the cards.

#### Is there a list of all special conditions or preferential treatment for European Disability Card holders?

There will not be a centralised EU resource listing the special conditions and preferential treatment for the European Disability Card holders across Member States. Nevertheless, the proposed Directive mandates Member States to ensure that private operators or public authorities make this information available for free in accessible and user-friendly formats.

Special conditions and preferential treatment for persons with disabilities may include free access, reduced fees, priority access, personal assistance, access to braille and audio guides), and mobility aids, among others. The special conditions and treatment for persons with disabilities vary across Member States.

#### When will the European Disability and Parking cards for persons with disabilities be available?

The Commission's proposal will first be discussed by the European Parliament and the Council. The proposal foresees that once adopted, Member States will have 18 months to incorporate the provisions of the Directive into national law. One year later, the legislation would become applicable, at which point persons with disabilities could apply for the cards.

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AUSTRIA - Cochlea Implantat Austria (CIA) - Summer Sun and Family Fun in Carinthia



This summer saw the 19th edition of Cochlea Implantat Austria's Summer Days in the posh lakeside village of Velden, Lake Wörthersee, in Carinthia (Austria).

Targeted at families with children with CI, attendees of these traditional days ranged from families with not-so-young-anymore kids (aka young adults) to families of recently implanted toddlers – all of them united by their cochlear implants.

More than 160 people enjoyed the relaxing atmosphere at the lake, where they shared their experiences with cochlear implants and learned from each other. "It is so cool to meet other children that have cochlear implants. I am the only one at school and in town with a CI, but here, my friends all have implants, so we all have similar issues", stated teenager Valentin.

While the adults received news from the CI field and exchanged valuable information, their kids were painting, crafting jewellery, playing music with professional musicians or acting in a theatre workshop. Swimming, banana boat rides, a visit to the zoo and a fancy dinner with live music in a beautiful castle made these five days fun for everyone.

The Family Olympics and the final show featuring the theatre and music groups were the highlights of the 2023 Summer Days. "The theatre Play that the kids put on stage within such a short time was simply amazing", said Birgit, mother of two sons with cochlear implants, full of enthusiasm. "It is so encouraging to see how well the teens and young adults do with their CIs, which makes me optimistic for the future of my two little ones", she continued.

If you want to relive the moments of the 2023 Summer Days, or be part of the 2024 Summer Days, click here.

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#### CZECH REPUBLIC - SUKI - By Experience to Understanding



# BY EXPERIENCE TO UNDERSTANDING – Project from EURO-CIU Czech member, SUKI. With EURO-CIU's help, it will be translated to several other languages.

The project focuses on the inclusion of hearing-impaired children (age 6-12). We address teachers, who work in mainstream basic schools and who have a Hard of Hearing or Cochlear Implant child in their class. Our target is to create materials easily applicable in lessons that would help teachers to better understand and adequately respond to the needs of their pupils with 7 different brochures dedicated to different kinds of educational situations:

- 1. Being parent to a child with a hearing impairment How to start elementary school
- 2. Teacher of a child with a hearing impairment
- 3. Teaching assistant for a child with a hearing impairment
- 4. Foreign language teacher of a child with a hearing impairment
- 5. Coach or PE Teacher of a child with a hearing impairment
- 6. A leisure educator of a child with a hearing impairment
- 7. After-school teacher for a child with a hearing impairment

https://eurociu.eu/educational-teachers-of-cochlear-implant-students-brochures/

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FINLAND - LapCI's trip to London & Brighton





This past summer LapCI (The Finnish Association of Cochlear Implant Recipient Children) organised a language trip to England for nine CI users aged between 14 and 16 and three supervisors. The main aims of this trip were to encourage CI teens to practice their English skills, inspire them take steps towards independence and, of course, to make new friends and memories along the way. When planning the trip, it was important to us from the get-go that we offer our teens a chance to truly challenge themselves with language learning, which is why we did not invite parents on this trip. One of the supervisors on the trip, however, was a CI user herself, so she was able to provide great insight into how to best make sure accessibility and hearing conditions were always prioritised.

We started our trip by travelling to London, where we met up with people from CICS (Cochlear implanted children's support group) and AVUK (Auditory verbal UK) for a lovely picnic in Green Park. After the picnic we all went together to see Mamma Mia! the musical and enjoyed a delicious pizza dinner to cap off the day. Our Finnish delegation 'adopted' a British CI-using teen (who connected with us through CICS earlier this year) for the week, meaning he was part of our group in all activities. This provided a great opportunity for the Finnish teens to practice English in everyday conversations throughout the week.

Our second day in London was spent doing sightseeing in two groups (one went to see Madame Tussauds and the London Bridge Experience, the other went on a guided Harry Potter tour around the city). We also had the time to visit London Eye before we had to pack up our bags and head to rainy Brighton.

In Brighton we had a week full of activities: a sushi making class (not everyone was a fan of raw fish, but a lot of fun was still had!), laser games, hiking to the Seven Sisters cliffs, bowling, visiting the Upside Down House and much more. On our last night in Brighton, we visited a local youth centre where we got to play various games and try our hand at making graffiti, which was a new experience for most of us. Every day the teens were also given a couple of hours of free time when they could go and explore the town by themselves.

The trip went smoothly, despite our Brighton lodging cancelling our booking due to a fire mere three days before our arrival. A real blessing in disguise, the replacement accommodation (a whole house all to ourselves!) we found in the nick of time worked out even better than what we had originally booked. Overall, this trip was a great success, and we hope to be able to do this again in the future. We would love to collaborate with other CI organisations around Europe, so if you're interested – hit us with an email! or our general email.

**Isa Pulli** CIsupaja Project Coordinator LapCI

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ITALY – AGUAV convention celebrated the record of Varese hospital reaching 2,000 cochlear implants.



More than 700 members were present at Villa Ponti on Sunday 11th June 2023 to celebrate the many achievements of the Audiology Department of Varese and those of AGUAV, the association that supports Varese Audiology Department, directed by Dr. Eliana Cristofari.

A great day from the scientific, cultural and emotional point of view.

In addition to being the first Italian centre to have reached 2,000 cochlear implants, in 30 years, the Audiology department of Varese is the first Italian hospital to have performed surgery with robotic surgery and to have operated on a child using 3D Exoscope vision.

In 1991, the first cochlear implant was inserted in an adult and, only a year later, the first deaf Italian child from birth was implanted at the age of 5 years. Since then, thanks to the tenacity and foresight of Dr Burdo, then head of the department, his group of pioneers and the newly founded association, AGUAV, the Audiovestibologia became a national attraction for deaf adults and children.

AGUAV, founded in 1997, has always supported the trans-disciplinary method of Varese that allows the patient to be taken in charge totally by all professional figures dealing with deafness, thanks to which it is possible to restore the hearing function of children and adults in a single location.

The President of the Lombardy Region, Attilio Fontana, stressed the importance of the Audiovestibule of Varese "which has become an excellence at the national level". In his speech he reiterated "with your interventions completely transform the lives of children who find themselves excluded from the world and who suddenly return to be part of it fully and completely. Thanks also to AGUAV, the Association intervenes where the public fails to arrive and helps all operators to feel more listened-to and appreciated. Associations are such a great reality and wealth of our territory so that in Lombardy we have institutionalized the function of associations."

From Rome the Minister of Disability Alessandra Locatelli sent a message highlighting the importance of cochlear implantation and the paths dedicated by Varese to the families of young patients who can have a look at the future of their children with confidence and surely greater satisfaction. He thanked the professional team of Audiovestibologia and AGUAV in supporting families, indicating the association as a model for anyone who wants to approach the third sector.

As the President of AGUAV, Paolo Bagatin, points out "our mission is to support the all-round Audiovestibologia of Varese, also through the dissemination of scientific progress on deafness and this year we were able to rent the robot for the surgical room with which Dr Cristofari performed the first surgery at Italian level".

During the Day, after the scientific convention held by surgeons, speech therapists and AGUAV board members, a huge variety of entertainment was offered to the kids and teenagers present at the convention. A fantastic meeting of CI users and their families from all over Italy, but also from Ukraine, Senegal and Spain after 3 years. See you next June with the same enthusiasm!

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THE NETHERLANDS - OPCI - Meningitis vaccinations and cochlear implants



The CI-ON (the consultative body of the CI centres in the Netherlands) has been working for years with the RIVM (the Dutch institute for infectious diseases) to make a recommendation around vaccinations related to meningitis in cochlear implantation.

This resulted in a technical document in spring 2023.

CI wearers were not much wiser from this. OPCI then contacted the RIVM to produce a more customer-friendly version of this.

RIVM made this possible and it resulted in the following document.

OPCI expects this to answer the questions that keep coming back about vaccinations. The document is in line with the overall vaccination advice which is common in the Netherlands for everyone.

### Vaccination advice for cochlear implant wearers and people with inner ear defects compiled by RIVM, arrived at through the efforts of OPCI.

Version: July 2023

Wearers of cochlear implants (CI), like people with inner ear defects, have an increased risk of meningitis. Encapsulated bacteria are a major cause of this: pneumococcal, meningococcal and hib (haemophilus influenzae type B). Therefore, a number of vaccinations against these bacteria are recommended preventively in CI wearers.

This advice has come about thanks to the cooperation of members of CI-ON (national consultation CI centres in the Netherlands) and RIVM (the Dutch institute for infectious diseases) staff and on the basis of international advice.

The treating ENT specialist of the CI team is the appropriate person to give the advice practical form in CI wearers. The general practitioner, any paediatrician and youth doctor can also play a role in this. For existing CI wearers (and new wearers outside the age categories shown), please refer to the vaccination schedule below. The advice also applies to persons with inner ear defects who are at increased risk of contracting meningitis.

In addition to vaccinations from the RVP (National Vaccination Programme)

The content of the vaccination schedule is based on the information prepared for healthcare providers and other professionals:

#### Vaccination advice for people with a cochlear implant | LCI guidelines (rivm.nl).

Please note that these are additional vaccinations to those given from the National Vaccination Programme at the youth health care consultation centre. Vaccinations within the RVP provide protection against bacteria causing pneumococcal, meningococcal and hib, among others.

Diseases to which CI wearers are particularly susceptible. This is all the more reason to get the RVP vaccinations offered. This also applies, for example, when visiting foreign countries. Vaccinations should preferably be obtained before cochlear implantation. The vaccines are inactivated vaccines so they can be given simultaneously.

Finally, this advice assumes that a person is at least 6 months old when the cochlear implant is placed and has had all the vaccinations in the National Vaccination Programme. If this is not the case or there are questions about the vaccination advice, we recommend contacting the practitioner, the GGD youth health care (consultation bureau), or the GP and getting the missing vaccines.

#### ROMANIA - Asociatia Asculta Viata - Hear Life Association



In May 2023, cochlear implants made from flowers were part of a flower-themed event in the medieval city of Sibiu. It was an unlikely but wonderful connection between centuries old buildings and the CI technological marvel.

Flowers on stairs (Rom: Flori pe Scari) event was part of the cultural agenda of Sibiu City Hall.

Last but not least, we had our summer camp during the last week of August. Once again, our members, children, teens and parents spent wonderful moments together, got updated on the latest news and products from the CI manufacturers, participated in team building activities and counselling sessions with professionals.

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SPAIN – Teatro Accesible (Accessible Theatre)



Last August, Sagunto held the Sangunt a Escena Theatre Festival, where plays adapted for people with hearing and/or visual loss were programmed for the first time. On the 12th August, a total of 8,000 people were able to enjoy the play La comedia de los errores (The Comedy of Errors) written by Shakespeare.

Federación AICE, together with the Teatro Accesible Project, made it possible for people with cochlear implants to have an effective access to culture, as they offered 10 induction loops free of charge to the audience. Moreover, the play was subtitled so that the script could also be read.

This event was a milestone in terms of cultural accessibility in the Valencian Community, in Spain. The members of Federación AICE who attended the play with their families and friends were very grateful, as they told us that it was the first play they had been able to attend since they started suffering from hearing loss. We hope, therefore, that this will become a regular way to ensure that every person – in spite of their circumstances – can achieve an active involvement in every single area of society, including art and theatre as well.

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SPAIN - Camp AICE



Once again this year, and this is the ninth edition, Federación AICE and all the volunteers put the finishing touches to CampAICE and its pioneering activities in Spain, which are becoming more and more successful every year among the youngest cochlear implant users. The camp is totally accessible for them thanks to the induction loops, live transcription and amplified sound, as well as having implanted monitors who were once participants and today are a reference for young people who attend the camp. It creates as an excellent connection as they see themselves reflected in each other.

They have worked on self-esteem by facing different situations that can be complex for a person with hearing impairment. Learning that all people are capable of overcoming situations that may not seem complex at first – such as dancing in front of others, asking for what you need or wearing a braid for several days so that the processor can be seen – can become an incredible challenge for cochlear implant users. Not being embarrassed and exposing ourselves to these situations is always so difficult, but everybody who has participated in CampAICE has overcome it with flying colours.

During the 9 days of the camp, young people of the Federación AICE have been able to enjoy a few days of disconnection in a safe environment, meeting people of their age, making friends for life, promoting their self-esteem and security through the activities, gathering information and opinions on the evolution of cochlear implanted youth in Spain, and especially having managed to make us feel proud, for their effort, their desire to excel and for never giving up.

Proud of yourselves! Proud of themselves!

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Lehnhardt Foundation with Online Counselling Centre for Russian-speaking immigrant families



Since February 2022 Liubov Wolowik (member of the board of the Lehnhardt Foundation) has been offering support for parents with children wearing a CI or adult CI-recipients from all over Germany, the Netherlands, Spain, Austria and Poland. The communication takes place via phone, WhatsApp, by email or in Zoom meetings.

Our main activities include:

- contacting employees from social service organizations in various cities to facilitate entry and search for an adequate apartment, organizing appointments with ENT doctors, CI clinics, hearing aid acousticians, service points for CI, CIC centres for inpatient rehabilitation after CI surgery, early intervention, kindergartens and schools
- translation on the phone in case google translate doesn't work
- explanation and translation of letters from various organizations regarding the hearing evaluation of the child
- delivery of speech processors and / or spare parts for the CI system for the time when the family does not yet have any insurance

Here are three examples from many more:

- 1. A young mother, Rimma, who had her cochlear implant for one year. She couldn't yet understand speech on the phone. Therefore, Liubov organized appointments with the audiologist, with the University Hospital in Frankfurt and also professional rehabilitation. She participated in the phone conversations and wrote the translation into Russian by WhatsApp.
- 2. For a mother with her son, Serhi, who wears a CI. Liubov established contact with a social service organization in Hessen to facilitate immigration and find a place to live. We then provided a speech processor and spare parts to a hearing aid acoustician in Friedberg (close to Frankfurt) because the boy's SP was broken, and the family had no insurance yet.
- 3. Another boy, Maxim, lives in a village far from the school for the hearing-impaired children in Stegen (near Freiburg im Breisgau in the South West of Germany). He could only attend school if he stayed at the boarding school. This was not acceptable for his parents. It took multiple and long conversations with the mother and the hearing aid acoustician. Translation of the documentation was prepared for the new school on site and rehabilitation was organized in the CIC Center Frankfurt. We provided spare parts for the old speech processor because they are not available and cannot be ordered with all hearing aid acousticians in Germany. The speech processor is only four years old and therefore it is too early to get an upgrade in Germany.

#### Volunteers are welcome!

Currently the support is organized by only one person. Number of requests in 18 months: over 250 (10-15 per month). Do you speak English/German and Russian? We look forward to your support! Please click here to email.

Liubov Wolowik

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RELATED CONGRESS – The 17th International Conference on Cochlear Implants and Other Implantable Technologies



21 to 24 February 2024

The 17th International Conference on Cochlear Implants and Other Implantable Technologies will gather in Las Palmas de Gran Canaria (Canary Islands, Spain) with prominent global experts in the field, including basic scientists, clinical specialists, and researchers. There will be very thorough clinical debates on various topics related to all fields in Cochlear Implantation and other Implantable Devices, as well as a special focus on Basic Sciences, including the most important research groups in the world.

The deadline for Abstracts is 15 November 2023.

For further details, please click on the conference website.

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RELATED CONGRESS - International Congress 2024 from The Dutch Association of Sudden and Late Deafened

**DUTCH ASSOCIATION OF SUDDEN & LATE DEAFENED** 

The Dutch Association for Sudden and Late Deafened is organising an international congress in 2024. It will take place on Friday 22, Saturday 23, and Sunday 24 March 2024 in Hotel Zuiderduin in Egmond aan Zee in The Netherlands. The theme of this congress is Let's connect 2!

After the success of the first international congress in 2014, on the occasion of the 25th anniversary, this event has become a tradition every five years, bringing together organisations from different countries to share knowledge and experience on the issues and possible solutions related to sudden and late deafness.

During this congress, we will pay attention to the needs of the Sudden and Late Deaf and seek solutions and best practices together with international sister organisations. This way we can learn from each other, exchange experiences and contribute to a more inclusive world for people with this invisible challenge. Let's connect!

The congress is intended for everyone who works with and for deaf and hard-of-hearing people, for interested parties, policymakers, fellow sufferers, experts by experience, interpreters, visionaries, and everyone else who is interested and wants to gain and/or share knowledge. The expected number of visitors from home and abroad is about 250.

Many of the Sudden and Late deafened are Cochlear Implant (CI) users. Therefore, all of the CI companies will be present at the congress to give visitors the latest information about their products. Also, other companies who work with and for our target group will be present.

For more information about the congress feel welcome to visit our website: Internationaal congres 2024 (stichtingplotsdoven.nl)

Gerard de Vijlder (chairman)

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RELATED CONGRESS – BATOD, FEAPDA & NCSE – Exploring the diversity of deaf learners in their many lives: implications for our knowledge and practice



BATOD (the British Association of Teachers of Deaf Children and Young People) is pleased to announce a joint Congress with FEAPDA (The European federation of national associations and organisations of professionals working with deaf children and young people) and with NCSE (National Council For Special Education in the Republic of Ireland). The Congress will take place on Friday 26th and Saturday 27th April 2024 in Dublin.

The theme is 'Exploring the diversity of deaf learners in their many lives: implications for our knowledge and practice.' Each deaf child or young person brings a unique experience to their education. The combination of their varying home cultures, their additional needs and their perspectives on their own lived experience raises questions about how to shape practice and monitor outcomes.

Visit our website page for further information and a call for contributions.

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#### RELATED CONGRESS – HeAL 2024 – Hearing Across the Lifespan



The next international HeAL 2024 conference (live) will be held from 6 to 8 June 2024 at our historic venue, the gorgeous Villa Erba Conference Center, on Lake Como in Cernobbio. This peaceful, elegant, cosy and little frequented town with all its charm will once again host our meeting.

HeAL meetings, a.k.a. the Como Conferences, have closely monitored – and contributed to – the progress of modern Audiology and Hearing Science, also influencing the development of clinical studies and practical protocols. HeAL meetings bring together experts from across disciplines and offer delegates a unique opportunity to discuss their latest research in a truly international forum.

The Scientific Program is usually composed of several parallel sessions and enriched by Satellite Events dedicated to a great variety of topical issues as well as Special Sessions and Mini-Symposia proposed and coordinated by many Organizations and Institutions active in the wide area of hearing research and hearing care.

Save-the-date. Come and join us for another exciting conference in Cernobbio in 2024!

#### Ferdi Grandori (Chair)

National Research Council of Italy – CNR-IEIIT – Institute of Electronics, Information Engineering and Telecommunications, Milan Unit based at the Dept. of Electronics, Information and Bioengineering, Polytechnic of Milan, Italy

#### **Scientific Committee**

Sophia E. Kramer, PhD at the Amsterdam UMC - location VU University Medical Center in Amsterdam, The Netherlands

**Alessia Paglialonga**, PhD National Research Council of Italy – CNR-IEIIT – Institute of Electronics, Information Engineering and Telecommunications, Milan Unit based at the Dept. of Electronics, Information and Bioengineering, Polytechnic of Milan, Italy

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**RELATED CONGRESS – CI2024 International** 

# C12024 VANCOUVER: 17<sup>TH</sup> INTERNATIONAL CONFERENCE on COCHLEAR IMPLANTS and OTHER IMPLANTABLE TECHNOLOGIES

July 10-13, 2024 | Vancouver, BC





#### Save the Date! CI2024 International - July 10-13, 2024

This international conference will foster the exchange of multi-disciplinary scientific information applicable to audiologists, physicians, speech pathologists, psychologists, scientists, engineers, educators, students, advocates, and others involved in cochlear and other implantation technology globally. The conference will provide attendees with opportunities to engage with fellow professionals exploring current and emerging topics for cochlear and other implant device patients across the lifespan.

Abstract submissions are now being accepted, with deadline 18 October 2023.

Anticipated session topics:

- Successful Pathways to Cochlear Implantation: A Global Perspective
- CI in SSD for Adults and Children: Candidacy, Provision, Outcomes
- Socio-emotional Health in Cochlear Implant Users
- CI Provision at Both Ends of the Age Spectrum: Under 6 months and over 90
- Optimized Models for Cochlear Implant Workflow
- Listening Impacts on Literacy and Learning in Children with Cochlear Implants
- Effects of the COVID Pandemic on Cochlear Implant Outcomes

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WORLD NEWS - Launch of new living guidelines for cochlear implantation in adults



# IMPROVING THE STANDARD OF CARE FOR ADULTS WITH HEARING LOSS AND THE ROLE OF COCHLEAR IMPLANTATION:

# LIVING GUIDELINES

Following a period of public consultation, a Taskforce of 52 hearing experts have released new Living Guidelines for hearing care. The recommendations provide guidelines and guidance for hearing professionals to improve the standard of hearing care for adults.

The new Living Guidelines provide 9 recommendations and 31 good practice statements across hearing screening, specialist referral and evaluation, rehabilitation, and patient outcomes.

The two-year research project looked at more than 13,000 peer-reviewed studies and involved a panel of 52 experts representing 58 organisations, including those living with hearing loss. The Task Force worked in partnership with CIICA, the CI International Community of Action (www.ciicanet.org) a global community of CI users, advocacy groups and professionals who support a shared vision of closing the global access gap in CI provision and ensuring lifelong support for all who could benefit. The involvement of the CIICA network accords with a core objective of the Taskforce: to ensure CI users are partners in creating the international Adult CI standard of care so that it meets their expectations. The ultimate goal of the Task Force was to agree on guidelines that not only improve outcomes for people living with hearing loss, but which are consistent and easy to follow. The guidelines will be updated as new evidence becomes available.

Following this launch, national professional societies and healthcare organisations have to look to adopt the guidelines into their clinical practice standards and the guidance.

To access the full online guidelines, click HERE. To find out more about the process and for more educational tools head to Living Guidelines: www.ciicanet.org and https://adulthearing.com/living-guidelines/.

An introduction video of the Living Guidelines for adult cochlear Implantation was developed by Pindrop (New Zealand) and CIICA: https://adulthearing.com/living-guidelines/

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WORLD NEWS - the World Hearing Forum

# WORLD HEARING FORUM

Interested in becoming a member of the World Hearing Forum and advocating for #hearingcare and #safelistening?

World Hearing Forum membership applications open now until 30 September 2023!

The World Hearing Forum is a global network of stakeholders promoting ear and hearing care worldwide. It includes three working groups:

- 1. Changemakers,
- 2. World Hearing Day, and
- 3. Make Listening Safe (MLS).

The World Hearing Forum is on the lookout for dynamic members to join and contribute to its activities and spread its messages worldwide.

Become a member.

EURO-CIU is a founding member of the World Hearing Forum

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WORLD NEWS – In older adults at increased risk for cognitive decline, hearing intervention slowed down loss of thinking and memory abilities by over 48% over 3 years.

ADDRESSANCIERS PRESSANT CONTACTUS C Address V Key Findings News Publication

A landmark study of the effect of hearing intervention on brain health in older adults

OUR NEY FINDINGS

ACHIEVE



Unaddressed hearing loss costs the world \$980 billion per year, roughly 1/3 is attributable to additional health care cost (1). Dementia poses a huge burden on patients, families, and society. The Lancet commission calculated, that 8% of dementia cases are attributable to midlife hearing loss (2). The big open question until now was, whether hearing restoration, such as hearing aids, would reduce the risk of dementia.

The Aging and Cognitive Health Evaluation in Elders (ACHIEVE) trial (3) was designed to determine exactly that. It recruited 977 study participants aged 70 to 84 with mild to moderate hearing loss, not using a hearing device. Participants were recruited from two sources; from an existing cardiovascular study (ARIC) and form the healthy, general population (de novo). Participants were then randomly assigned to a hearing intervention group (receiving hearing aids) and a successful aging health education group (receiving health education). Their cognitive functioning was monitored over three years.

After three years, there was no difference in cognitive decline between the hearing aid and the health education group. However, when analysing the "ARIC" and the "de novo" group separately, the "ARIC" group who received hearing aids showed a 48% reduced cognitive decline, compared to the "ARIC" group who received health education. There was no such difference in the "de novo" group. Compared to the "de novo" group, participants in the "ARIC" group had more risk factors for cognitive decline and dementia, they were older, more likely to live alone and had already at the beginning of the study lower cognitive scores. The authors summarize the findings: "In older adults at increased risk for cognitive decline, hearing intervention slowed down loss of thinking and memory abilities by over 48% over 3 years." (4)

Why is this important? In a world, where people put more than twice as much priority in taking the pet to the vet than in having their hearing checked (5) and primary physicians find it 33-times more important to manage heart disease than hearing (6), the ACHIEVE study outcomes may contribute to an adequate priorisation of hearing health; channelling research funds and policy change into the right direction.

The ACHIEVE study maintains its dedicated website https://www.achievestudy.org/about where summaries and infographics can be downloaded and used, e.g. for advocacy work with decision makers.

(1) World report on hearing. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO. p. 49)

(2) (Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. The Lancet. 2020 Aug 8;396(10248):413-46.)
(3) ) Lin FR, Pike JR, Albert MS, Arnold M, Burgard S, Chisolm T, Couper D, Deal JA, Goman AM, Glynn NW, Gmelin T. Hearing intervention versus health education control to reduce cognitive decline in older adults with hearing loss in the USA (ACHIEVE): a multicentre, randomised controlled trial. The Lancet. 2023 Jul 17.

(4) https://www.achievestudy.org/key-findings

(5) Carlson ML, Nassiri AM, Marinelli JP, Lohse CM, Sydlowski SA. Awareness, perceptions, and literacy surrounding hearing loss and hearing rehabilitation among the adult population in the United States. Otology & Neurotology. 2022 Mar;43(3):e323.
(6) Sydlowski SA, Marinelli JP, Lohse CM, Carlson ML. Hearing health perceptions and literacy among primary healthcare providers in the United States: a national cross-sectional survey. Otology & Neurotology. 2022 Sep;43(8):894.

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WORLD NEWS – EHIMA – New public information portal HearingYou.org provides authoritative data about hearing health.



In Europe, 11.1% of the population report having a hearing loss. Yet many do not seek or do not receive adequate care in the form of hearing screening or rehabilitative technologies such as hearing aids and implants. A mere 33% of people living with self-assessed hearing loss are estimated to use hearing aids. Lack of awareness among policy makers, health professionals and even hearing-impaired people themselves hinders prevention and access to rehabilitation.

A new public information portal aims to change this: HearingYou.org is designed to be an authoritative gateway to raise awareness of the importance of hearing health as a public health issue. It has been launched by the European Hearing Instrument Manufacturers Association

(EHIMA) to provide a global audience with information on all aspects of hearing health, including hearing loss prevention and rehabilitation, and to support effective policy measures against hearing loss. The centrepiece of the site is a data hub with the latest research, scientific evidence, facts and figures on the prevalence of hearing loss, its economic impact and how hearing loss is linked to chronic diseases such as dementia.

HearingYou.org brings together EHIMA's internationally standardized "EuroTrak" surveys in one place, making it the largest source of comparable data on hearing health. EuroTrak is the most comprehensive multi-country study of hearing loss and hearing aid use. In addition to the US-focused MarkeTrak surveys, EuroTrak surveys measure self-reported hearing loss and use of professional hearing care in major European and Asia-Pacific countries. This allows HearingYou.org to act as an evidence hub for policy makers to help them design effective hearing care policies.

EHIMA Secretary General Dr. Stefan Zimmer points out: "The age structure of many societies is changing rapidly. Hearing health is destined to become a defining feature of future-proof policies. Only what is measured can be managed, and HearingYou.org provides easy-to-find information for well-informed public policy. This would enable hearing impaired people to lead empowered and mobile lives."

The new website includes information from EHIMA and its hearing care partners, such as the European Association of Cochlear Implant Users (EURO-CIU), the European Federation of Hard of Hearing People (EFHOH), the European Association of Hearing Aid Professionals (AEA), the International Federation of Hard of Hearing People (IFHOH), and other international and national associations and groups active in the field of hearing care.

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#### WORLD NEWS - Denmark - TRAP UP



A platform of knowledge sharing and best practice to create the best possible school life for deaf and hard of hearing pupils.

#### Click here: Trapup for the TRAP UP website

TRAP UP (Transnational Professional Upgrading Project) is a web platform, which contains information, materials and concepts to use with deaf and hard of hearing pupils. The pupils may be using Cochlear Implants, Hearing Aids or Bone Anchored Hearing Systems, and the target groups include children communicating either in spoken or in sign language.

TRAP UP is an innovation and development project granted by the Erasmus+ programme. The project ran from September 2020 to August 2023 and ended with an open conference. See the 1.5 hour presentation here: https://www.youtube.com/@trap-uperasmusprogram706

Professionals from four different countries have participated and developed the platform:

- Center for Communication and Welfare Technology, Hearing counselling children and young people, Fredericia, Denmark.
- · State Centre for Hearing and Communication (Schleswig), Germany

- Valteri Centre for Learning Consulting, Finland
- Institute for the Deaf and Hard of hearing Ljubljana, Slovenia

The purpose of this platform is to raise awareness and share and increase specialized knowledge in teaching deaf and hard of hearing pupils. We aim to inspire each other to make the best practice for teaching deaf and hard of hearing pupils and to ensure their access in life, educationally and socially.

The website is accessible for everyone who have interest. Whether it is professionals working with deaf or hard of hearing pupils or parents, who are interested in learning more.

All content is available in English and in German, Slovenian, Finnish and Danish, which represents the participating countries behind the project.

All content on this website is free of charge and all users have access to all materials and concepts.

The materials/concepts are:

- Classroom design a guide to get best classroom conditions for DHH pupils.
- E-learning course on inclusion of pupils with hearing loss for teachers and other professionals
- Teaching material to learn the native spoken language and the native sign language
- Distance teaching instructional videos and guides on how to model distance teaching for pupils in local schools to access qualified teaching.

Furthermore, in "Learn more about the project" you can learn about the processes in developing this platform, statements from teachers testing the materials and find guides and recommendations on how to adapt and implement materials and concepts into own languages, cultures and countries.

The impact evaluation of the test-teachers showed that 85% of the teachers are now acting differently in the classrooms after seeing and using the TRAP UP materials.

If you have questions regarding the project, the materials or anything else regarding teaching deaf and hard of hearing pupils, please go to Contacts at Trapup

Project manager Ulla Carl, Center for Communication and Welfare Technology, Fredericia, Denmark: ulla.carl@rsyd.dk

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WORLD NEWS – the Netherlands



Congratulations to Prof. Dr. Emmanuel Mylanus who has been nominated to be a Professor in Otology-implantology in Nijmegen. For about the last 6 years he has been a visiting professor at the University of Ghent, Belgium. His inaugural lecture as a Nijmegen Professor will be at the University in Nijmegen on Friday 6 October at 3:45 pm.

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WORLD NEWS – UK – AVUK – Claire Campbell Award open for nominations recognising outstanding achievements of deaf children and adults supporting them.

# Claire Campbell Outstanding Achievement Awards



# Recognising the achievements of deaf children and young people, and the adults who support them

# **Enter now**

The Claire Campbell Outstanding Achievement Awards have been launched in memory of Claire who was a committed volunteer and ambassador of Auditory Verbal UK up until her death in November 2022.

Claire was the mother of three children, two of whom are deaf and wear cochlear implants. They attended Auditory Verbal UK's family programme as young children, and the family became committed to helping more deaf children have the same support.

Clare's husband Chris said: "Claire was passionately determined that being born deaf would not stop our children, Alice and Ollie from achieving everything they were capable of. Learning to listen and speak with AVUK has undoubtedly meant that they have been able not only to have an equal start in life, but also to become inspirational children who demonstrate that everything is possible.

"Claire was committed to ensuring all other families with deaf children should have the same opportunity. She will never be forgotten, not least for the support she gave her own children, to so many families and how she fought to raise awareness and the need for greater investment in support for deaf children. Now we want to recognise the outstanding achievement of other deaf children and individuals who support them just as Claire did."

There are two categories for:

- deaf children and young people who have gone above and beyond to raise expectations of what deaf children can achieve;
- Adults, such as professionals, parents or caregivers, who have gone above and beyond in support of deaf children.

Entries are welcome from the UK and overseas and close on September 24th. More information is available on the award page.

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WORLD NEWS - UK - AVUK feature in BBC Documentary



#### Photos: Rose & Noel (left & right), and Rose & Harrison (centre)

AVUK was excited to be involved in a BBC television documentary "Signs for Change" presented by deaf actor and advocate Rose Ayling-Ellis in June. Rose visited AVUK's London Centre meeting Senior Auditory Verbal Therapist Noel Kenely who explained how Auditory Verbal therapy works supporting deaf babies and children whose families want them to learn to listen and speak.

Noel showed Rose videos of Lola, who was born profoundly deaf and wears cochlear implants. Now 6 years old the videos show Lola, who is bilingual in English and French and is learning Spanish, interacting and speaking with Noel during one of the family's Auditory Verbal therapy sessions, delivered online.

Rose also met 26-year-old Harrison who wears cochlear implants and also attended an Auditory Verbal therapy programme when he was younger.

The documentary (available on BBC iPlayer) follows Rose on her personal journey and asks whether attitudes towards deaf people are changing in the UK. It also looks at what is needed to support deaf people so they can reach their potential and live rich and fulfilling lives and raises awareness of what deaf children and adults can achieve with early and effective support, whether they use sign language, spoken language or both.

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WORLD NEWS - UK - AVUK - Academic Success for young deaf students



#### Photos: Enjkhin & Imuujin (left) and Charlie (right)

We've been celebrating academic success by Auditory Verbal UK graduates with cochlear implants who attended our family programme when they were young.

Enjkhin Tserendorj will start her undergraduate degree course studying bio-medicine at Queen Mary University, London, this month.

She was diagnosed as deaf soon after she was born and received cochlear implants aged two and three. She attended Auditory Verbal UK's family programme for two years before graduating with age-appropriate listening and speaking and attending mainstream school.

Enjkhin is also a talented artist and has met King Charles at an art workshop held in Buckingham Palace.

Charlie Denton (16) not only achieved wonderful General Certificate of Secondary Education (GCSE) results but will also be representing TEAM GB at the World Deaf Tennis Championship in Greece this month.

Charlie is a talented musician as well as sportsman playing the violin, piano, guitar and drums.

He received his cochlear implants aged three and attended AVUK's family programme. He graduated from the Auditory Verbal therapy programme with speaking listening skills on a par with hearing children.

He said: "My ambition now is to retain my National Deaf Tennis Junior Singles and Doubles titles next month, continue my studies with A levels in Psychology, Sports Science, Business and Classical Civilisation and get selected for the Deaflympics in Tokyo 2025. AVUK taught me never to give up and I think you can see I never have!"

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WORLD NEWS – UK – British Association of Teachers of Deaf Children and Young People – BATOD Audiology Refreshers resource

BATOD held a soft launch of the Audiology Refreshers digital open-access resource on the 21st June.

This BATOD project is funded by the William Demant Foundation, working in partnership with DeafKidz International (DKI) who are coordinating the project, along with the British Society of Audiology, the lead partner.

Six working groups made up of dedicated chairs, co-chairs and experts working in deaf education, audiology and technology across the UK have been developing new and updated content on:

**British Association of Teachers of** 

**Deaf Children and Young People** 

- 1. Anatomy and physiology
- 2. Aetiology and types of deafness
- 3. Auditory perception and hearing testing
- 4. Acoustics and physics of sound
- 5. Listening skills and functional hearing
- 6. Hearing technologies and assistive listening devices

The Audiology Refresher resource was originally conceived by Margaret Glasgow and were published as a series over several years in issues of the BATOD Magazine. The mandatory qualification training for Teachers of Deaf Children and Young People includes basic audiology. The audiological knowledge required to support deaf children and young people is wide ranging. Margaret, and colleagues, authored a series of articles to give Qualified Teachers of Deaf Children and Young People (QToDs), students, and other professionals working with deaf children quick access to refresh their memory of basic audiological knowledge and practices. The resource was last updated in 2009 and this project has offered the opportunity to seek the views of students, QToDs and associated professionals to help shape and lead this vital update.

Following on from the initial webinar, BATOD is collecting comments and feedback from professionals about the content developed so far, through email and through a post-webinar survey to gather more in-depth feedback for analysis and future development. The survey is currently live to late September. It has 15 questions and takes about five minutes to complete. Your feedback would be welcomed too.

In addition, the working groups will continue to develop content for the resource, with plans for a full launch on Tuesday 3rd October from 3:30 to 5pm. Details to be published soon on the BATOD events page https://www.batod.org.uk/events/. However, the work will not stop here, as BATOD will continue to review and update the resources as practices and technology develop.

If you have any feedback or wish to be involved in this exciting project, please reach out to us by emailing us here: BATODAudiologyRefreshers@batod.org.uk

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WORLD NEWS - USA - American Cochlear Implant Alliance Update



ACI Alliance Task Force Guidelines for Clinical Assessment and Management of Cochlear Implantation in Children and Adults with Bilateral & Single-Sided Deafness

Ear & Hearing has published the first three papers by ACI Alliance Task Forces on CI candidacy and management. The Task Forces were assembled to provide clarity on candidacy determination for adults (bilateral deafness and SSD) and children (bilateral deafness and SSD).

We are grateful for the important collaborative work of the task forces in helping promote broader understanding of candidacy determination and management in these populations. Read all the papers here and see the infographics that support them. https://www.acialliance.org /page/DeterminingCICandidacy

#### Tuesday Talks | Cochlear Implant Consumer Advocacy Network Members Lead the Way

Tuesday Talks are a free, captioned webinar series hosted by ACI Alliance. The content is designed for adults, parents, and others seeking information on cochlear implantation and related topics. Members of the CI CAN consumer network play a pivotal role in each presentation

by bringing their own experience with CI to the discussion. All talks are recorded posted for free online. https://www.acialliance.org /page/TuesdayTalks

#### LISTENING - LANGUAGE - LITERACY FOR ALL DEAF AND HARD OF HEARING CHILDREN: A COLLABORATIVE INITIATIVE

A task force of individuals who support families of children who are deaf and hard of hearing recently completed a 5-month collaborative process to develop research-based messages on the benefits of listening for language development and literacy. The group included parents of adult children born deaf or hard of hearing, adults who grew up with hearing loss, and professionals in the field of childhood hearing loss (including educators, audiologists, speech pathologists, a surgeon, psychologists, and early intervention experts). The collaborative effort relied upon earlier work by others including Dr. Dana Suskind's Thirty Million Words: Building a Child's Brain and guidance from pediatric nurses on "Language Nutrition," a concept emphasizing the role of families in providing home language that is rich in quality and quantity. The Language Nutrition concept applies to language learning for all children but is even more critical for deaf and hard of hearing children. The task force exploration led them to public and private school educators in Georgia who have initiated an effort to encourage parents to use the language of the home to talk, interact, read, and engage with their children. https://www.acialliance.org/page/awareness\_initiative

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#### Advanced Bionics - Empowering families in their journey towards better hearing



"What if you could provide a service that is so appropriate for a particular person, that it is exactly what they need at this moment of time?" (J. Pine) And help them and their family on their journey to hearing choose a hearing solution based on their needs, wishes and dream, as well as on the level of hearing loss? And then continue supporting them in the future with information, practical tips and tools. Wouldn't that be something? ....

The **myHearingGuide™ hearing journey coach app** from Advanced Bionics provides support to families learning about hearing loss, and helps them take those first steps on their journey (back) to hearing.

More importantly, it shows them that hearing loss does not need to be a barrier to connections, confidence & participation! It doesn't stop there though. The app also aims to:

- Help families figure out what they want and need, and how they can reach for the stars while keeping their feet on the ground.
- Find the right hearing solution for them.
- Keep track of the progress made and capture memorable moments (and celebrate them!).
- · Inform them about hearing loss and other hearing technologies.
- Provide support before and after receiving their hearing technology and connect them to helpful resources.

The myHearingGuide app also helps professionals gain awareness of solutions when hearing aids are no longer sufficient, increase their confidence when talking about cochlear implantation, implement family-centred care in their practice, and provide remote hearing care. The app is available for iOS and Android devices. If you like more information, please reach out to your local AB representative.

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Meet Jack, AB recipient and CI mentor since more than six years now. In this article, he tells us his experience being a CI mentor, and why this is such an important help for other candidates and recipients: "Recently, I was reading entries on the Advanced Bionics Facebook page. A wife was pleading for help for her husband, who was giving up on using his processor. He had no one to talk to and wasn't prepared for the issues he was having. Someone mentioned to the woman that her husband should speak to a cochlear implant mentor to get ideas and maybe find some answers. The wife was totally unaware of mentors."

With so much missing or misleading information out there on the Internet about cochlear implants, it is important to have an avenue for obtaining the correct information: "Many people understandably feel that information directly from cochlear implant companies may be biased. And their own hearing care professionals often only have a finite amount of time to educate them and answer all their questions. That's why we feel that we can help by sharing our lived experiences with these individuals."

Mentors are an extremely important resource before, and after receiving a cochlear implant, for recipients, but also for patient's loved ones: **"When there is hearing loss, not only is the patient affected, but also the people closest to them**. And they will continue to be a significant part of the journey towards better hearing. So, it's important to include them in the process. Furthermore, when these spouses meet and speak with my wife, they also feel heard, supported, and encouraged."

If you want to learn more about Jack and our mentors, you can read his article on CONNECTIONS. 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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Cochlear - a must-read guide for battery life



#### How long will my batteries last and what affects their life?

Did you know that daily battery life varies for every sound processor user and is dependent on a variety of factors?

#### A quick battery guide for Cochlear sound processors:

Firstly, it's beneficial to understand the difference between battery life and battery lifespan. 'Battery life' is the amount of time your device runs before it needs to be recharged. 'Battery lifespan' is how long your battery lasts until it needs to be replaced.

#### Nucleus® Kanso® 2 Sound Processor

The Kanso 2 Sound Processor has a built-in, rechargeable battery with an expected battery life of up to 18 hours.<sup>^</sup> The Kanso 2 Sound Processor uses an all-in-one home charger that charges, stores and dries your device at the same time. A portable charger is also available.

#### Nucleus® 8 Sound Processor

You can use disposable or rechargeable batteries with the Nucleus 8.

It offers a typical battery life of 35 hours using zinc air disposable batteries.^

For the rechargeable options, the Nucleus 8 Sound Processor has a Compact Battery Module which offers a typical battery life of 10 hours and a Power Extend Battery Module which offers a typical battery life of 20 hours.<sup>^</sup>

#### 6 tips to get more out of your battery life

#### 1. Don't let your battery completely run down without recharging

In the past, rechargeable batteries needed to be fully run down before recharging. But the newer lithium-ion batteries used with Cochlear sound processors will have a shorter lifespan if you let them become completely flat before recharging.

#### 2. Fully charge the battery with each charging cycle

Charge your batteries to their maximum capacity and remember to fully charge your batteries before storing them.

#### 3. Store batteries at room temperature if possible

Don't leave your batteries in a hot car or in direct sunlight; they really don't like excessive heat or cold.

#### 4. Rotate your batteries daily if you have several of them

Don't use one battery and store the others for later. It's better to rotate each battery each time you use it.

#### 5. Replace your batteries when needed

All batteries will degrade as they age, so when your battery no longer provides you with enough power for your daily needs, it's time to replace the battery. Your sound processor will alert you to a low battery status.

#### 6. Set your sound processor to turn off when you remove it

To save battery life, the Nucleus® 8 and Kanso 2 sound processors, allow your clinician to set the processor to turn off two minutes after you take them off. Ask your clinician for advice.

Follow this link to learn more about our latest sound processor models.

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Please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always follow the instructions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information.

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\*Battery life varies for every user, according to the age of the battery, the programs used each day, your implant type, the thickness of skin covering your implant, and the size and type of battery used. Streaming from compatible devices, True Wireless devices or FM may decrease sound processor battery life depending on how often and for how long streaming is engaged.

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#### Cochlear - A mum's tips for keeping a child's sound processor secure



Roxi, the mum of six-year-old Christian, struggled to keep her son connected with hearing aids, even before he had a cochlear implant and a sound processor.

As any parent of a young child with assistive technology knows, keeping the device safe is an ongoing task. Roxi has learned many lessons along the way with Christian, about helping him to keep his device in place.

"For the N8, we used the behind-the-ear clip but he doesn't like his ears cupped, so we are trialling a mould-in-the ear component," says Roxi.

The Cochlear™ Earmould Adaptor allows you to attach a custom earmould to the Cochlear™ Nucleus 8 Sound Processor. It can be a useful retention option for children or those who are comfortable using an earmould, such as former hearing aid users. (For more details see below.)

Device retention has other important benefits; longer periods of device use have been shown to improve hearing performance outcomes 1-3, so good retention is critical in achieving this goal. You can monitor time in speech using 'Hearing Tracker', a feature of the Cochlear Nucleus Smart App.

"I also ensure he has enough breaks without chastising him for it, and I remind him that his brain needs time to learn to adjust to the sound processor – and that's going to happen only if he actually wears it consistently and practises listening with dedicated attention."

Cochlear provides a wide range of retention options to help keep the sound processor securely on a child's head, especially during physical activities and sports.

For details about retention options for Cochlear's latest sound processors, follow this link.

#### References

1.Easwar V, Sanfilippo J, Papsin B, Gordon K. Impact of consistency in daily device use on speech perception abilities in children with cochlear implants: datalogging evidence. Journal of the American Academy of Audiology. 2018 Oct;29(09):835-46.

Wiseman KB, Warner-Czyz AD, Kwon S, Fiorentino K, Sweeney M. Relationships between daily device use and early communication outcomes in young children with cochlear implants. Ear and Hearing. 2021 Jul 1;42(4):1042-53.
 Gagnon EB, Eskridge H, Brown KD, Park LR. The impact of cumulative cochlear implant wear time on spoken language outcomes at age 3 years. Journal of Speech, Language, and Hearing Research. 2021 Apr 14;64(4):1369-75.

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Views expressed are those of the individual. Consult your health professional to determine if you are a candidate for Cochlear technology.

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#### MED-EL - Supporting Teachers of Children with Cochlear Implants



School has started again, and children are settling into their classrooms. To help your little one get the best school experience and achieve academic success, they might need some support to facilitate learning, especially if their teacher or teaching assistant has never taught a child with cochlear implants before.

To ensure that everyone in the classroom benefits from their time at school, we've collated a few helpful essentials that you can share with educators:

- 1. <u>Get to know the audio processor basics</u>: If your child is too young to handle the audio processor themselves, take some time to show the teacher the basics such as changing batteries or checking the cable. MED-EL offers some Quick Guides for the SONNET and RONDO series that you can share with the school (go to medel.com and search 'Quick Guide' and the name of your child's audio processor).
- 2. <u>A quiet classroom benefits everybody</u>: By optimizing the listening environment in the classroom, all students, no matter how good their hearing, will be able to hear instructions better. For students with CIs, a quiet environment with little background noise, and enhanced classroom acoustics using rugs and curtains, can make a huge difference. Teachers using ALDs will also facilitate listening and learning for students with CIs, hearing aids, or other implant types.
- 3. <u>Classroom seating</u>: Seating in the classroom is important for children with Cls. They should ideally be near the front, with a good view of the teacher's face. Educators should keep this in mind when they change seating throughout the year.
- 4. <u>Write it down</u>: All students will benefit if teachers write important information on the board, such as homework assignments or dates for exams.

These are just a few simple steps that teachers can make to optimize learning conditions for students with cochlear implants. It is important

that they know about them. Many more tips and easy-to-implement adjustments for school can be found in this useful article that parents can share with their child's teachers.

Read more:

- Tips For Teachers of Students with Cochlear Implants The MED-EL Blog (medel.com)
- Supporting Your Child With a Cochlear Implant at School The MED-EL Blog (medel.com)

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MED-EL – Hearpeers Hits 100 Volunteer Mentors Worldwide!

# hear 0 peers

Deciding whether to have a cochlear implant or not is probably among the most difficult decisions a person makes. There's a lot to think about and ask! Thanks to a global network of volunteers, people can now choose from over 100 Hearpeers Mentors from 20 countries to connect with, chat and ask about life with an implant.

Olga, a Hearpeers Mentor from Germany, explained why she became a Mentor after choosing an implant for her daughter; "I want to help parents of children with hearing loss because the diagnosis can leave them feeling completely helpless, and they'll have so many fears about their child's future – we know how that feels! My aim is to share my experiences, give parents confidence, calm their fears and make clear just how well a child can develop if they have hearing implants and are given the right support."

The number of Hearpeers Mentors is growing every month with new volunteers from Brazil, Nigeria, Italy, Slovakia, Czechia, and Slovenia joining this year. You can talk to someone who wears implants themselves, or like Olga is a parent of a child with hearing loss. Mentors will even share their own stories, challenges along the way, and life hacks – and of course answer any questions you might have that you might not want to ask your audiologist or surgeon.

To connect with a Mentor one-to-one and for free, head to the Hearpeers website.

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