



June 2024
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Message from the President



Photos: the Board on the left; and Robert Mandara on the right

A very long winter suddenly turned to summer here in Finland, where we have enjoyed the warmest and driest May on record. I hope that you are all prepared for summer, with waterproof CI covers for swimming, as well as hats and drying boxes to protect your CIs from sweat.

You may have seen the recent exciting news from the UK about the first successful gene therapy treatment to restore hearing. This is the first step on a very long road, but one can't help but wonder what it will mean for cochlear implants. For sure, nothing is going to change overnight. Over 400 genes relate to hearing loss, and this therapy targets just one of them. There are many open questions and nobody knows how long the treatment will last. Besides, gene therapy will not restore all kinds of hearing loss, so CI certainly has a future. As often is the case, there are a range of views on this development but, at EURO-CIU, I hope that we warmly welcome and encourage research into this new possibility to restore hearing.

There is a risk that CI candidates may be tempted to wait for this new treatment to become available. If you are a candidate for CI, it is important that you can hear now, not to lose decades to deafness, waiting for what might never come.

For the first time since 2019, EURO-CIU in conjunction with SUKI, will be holding a summer camp for young CI users in July, in Czech Republic. The camp is fully subscribed already. Besides providing fun and peer support for participants, the camp is really important to inspire the CI advocates of tomorrow.

The board of EURO-CIU wish you all a lovely summer!

Robert Mandara (President, EURO-CIU)

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Message from the Editor of the EURO-CIU Newsletter



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; and to those who have told us about forthcoming conferences.

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 September, so please let me have your articles and jpg photos by Monday 2 September 2024. 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 – 14th International EURO-CIU Symposium and General Assembly



The 14th International EURO-CIU Symposium and GA was hosted by Cochlea Implantat Austria (CIA) on 5th and 6th April respectively, at the Hauptbahnhof Novotel in Vienna.

Early arrivals were able to take a tour of The Josephinum Medical History Museum, led by walking encyclopaedia of CI, Prof. Dr. Wolf-Dieter Baumgartner. The museum currently has a large exhibition related to hearing.

The Symposium “Steps on the way to hearing with cochlear implants” was attended by around 100 people.

A wide range of topics was covered, including screening, rehabilitation, music, Usher syndrome, patient associations, and what we can expect to see in the future. Three round tables were held, covering what rehab should include, the challenges faced by teens and young adults with CI, and the effect of CI on social life, employment and quality of life. The Symposium was followed by dinner at Campusbräu restaurant.

Following the well-attended and lively General Assembly, delegates were able to enjoy a fascinating 1 hour tour on an antique tram around Vienna, followed by dinner at Melker Stiftskeller restaurant.

Cochlea Implantat Austria (CIA) has kindly put together a couple of links which may interest you:

[A Programme Review](#), with links to some of the presentations. Some more materials will come up on this page during the year. CIA are asking everyone please to stay tuned!

[A Gallery of photos taken](#) - at the Welcome Reception, the Symposium and the General Assembly - there are a lot of photos, so do enjoy looking at them.

Many thanks to CIA not only for organising our time in Vienna, but putting together these links.

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[EURO-CIU NEWS – the Summer Camp 2024 in the Czech Republic is fully subscribed!](#)



EURO-CIU is welcoming up to four youngsters from individual EURO-CIU member associations, aged 14–17 inclusive, with an adult leader, to the charming town of Telč, Czech Republic, from 20th to 27th of July.

The EURO-CIU Summer Camp will offer an action-packed week of fun and educational activities for young CI users from all around Europe. SUKI, the cochlear implant association from Czech Republic, will use their extensive experience to organize the camp on behalf of EURO-CIU. Their group of passionate young people will lead a week full of entertainment under the expert guidance of SUKI Vice-President Marína Štibranyi.

It's great that it is now fully subscribed, and we look forward to reading about the EURO-CIU Summer Camp 2024 in a future edition of this newsletter!

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[EURO-CIU NEWS – Stichting Plots & Laat Doven “Let’s connect 2!”](#)



Photos: left-hand a selection of photos from the Congress, right-hand Robert Mandara

The Stichting Plots & Laat Doven “Let’s connect 2!” International congress was held 22nd-24th March, in Egmond Aan Zee, The Netherlands. EURO-CIU’s President, Robert Mandara, was invited to speak there on the subject of CI advocacy challenges.

Around 100 people attended, and the majority were deaf, using hearing aids or cochlear implants. Most attendees were from The Netherlands, but some came from as far afield as the USA. The atmosphere was very warm, friendly and inclusive.

Delegates could choose to attend one of up to five parallel sessions. Therefore, it was not possible for everyone to participate in everything. Topics were generally focused on how to live and work healthily with deafness.

The congress was opened, in person, by Her Royal Highness Princess Petra Laurentien of the Netherlands. She has a genuine interest in hearing loss and made great suggestions for how we can advocate to help ourselves. She reminded us not to play down the scale of the challenges we face. Sometimes it helps to make a problem bigger.

Accessibility was very good as far as induction loops and sign language interpretation were concerned. Captions sometimes fell short when Dutch and English captions got jumbled.

On the first evening, Brad Ingrao and Eric Habets provided musical entertainment. During Brad’s performance of Take 5, the enthusiastic and impromptu actions of the sign language interpreters made it really unforgettable and fun.

A highlight of the congress was Brad Ingrao’s “Can we try that in Bb? Redefining your relationship with music after hearing loss”. Brad made us think about how well we can hear rhythms, pitches, instruments, and gave us a better understanding of why some music is easier for us to fathom with CI than others.

On the second evening, we had a great dinner with entertainment in the form of the Dutch signing choir, deaf stand-up comedians and karaoke.

After the congress, a large bus took delegates to Harlem, where they could go on a river

boat trip and/or visit a Teyler's Museum, the oldest museum in The Netherlands.

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EURO-CIU NEWS – CIICA Advocacy in Action Conference



The first CIICA Advocacy in Action Conference took place 9th - 10th of May 2024, at the Maison des Associations Internationales in Brussels.

Around 100 people attended, from all around the globe, and over 35 of them were CI users.

Accessibility was excellent, with induction loop and captions provided in several languages. The technicians and captioners did a brilliant job.

The conference was opened with a very special pre-recorded video message from Dr. Graeme Clark.

A very wide variety of ~10 minute presentations were made over the course of the two days. There was no time to get bored! EURO-CIU (Robert Mandara) made a presentation

on “Ethics, Conductors and Arbiters”.

While it is difficult to choose, these are just a few of the highlights.

Delegates were particularly moved when listening to the panel of young adults with CI. Although the panel have grown up in different parts of the world, it was interesting to hear the similarities in the experiences and concerns that they share. These young people are very smart, sociable and eloquent, a credit to their families, and a testament to the transformative power of CI.

Perhaps the moment of greatest visual impact was when Darja Pajk, while talking about “Managing the technology” held up the crazy spaghetti of cables and adapters that she has to carry with her whenever she travels, as a challenge to manufacturers to address the problem.

For individual advocacy determination, special mention must go to Kathryn Chlosta who set out the economic case for expanding adult bilateral CI access in The Netherlands. Her tenacity to collect the relevant data and then present it in an easily understood way, sets an example that all advocates should follow!

On the evening of 9th May, we went to dinner at the local La Cocina restaurant. The weather was nice, so were able to eat outside, where it was easy to mingle. Many of the delegates had met online previously, so they really enjoyed this opportunity to finally meet face to face.

Robert Mandara (EURO-CIU President)

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[CIICA Launches a New Practical Advocacy Guide](#)



Cochlear implantation (CI) is recognized as a life-changing and cost-effective intervention for individuals with severe or profound hearing loss which benefits society by improving communication and well-being. However, access to CI and ongoing support is limited in many countries globally, with only 1 in 20 of those who could benefit able access CI.

Current advances in access to CI and support services have only happened because of the energetic and persistent advocacy and campaigning of user groups and individuals locally, supported by committed professionals and industry. However, access to CI and services remains low: continued effort in individual regions and countries as well as globally is needed to ensure the promise of better communication through hearing well can be achieved.

This guide aims to support user advocates, professionals and all those campaigning to improve aspects of CI access and provision of services. It is based on a series of case studies of successful campaigns, many undertaken by CIICA members, to help advocates think about what would be relevant to their campaigns. It also outlines an overall plan for improving CI provision and links to other examples, resources and advice for advocates. With this guide we want to encourage unified voices and action to increase access to CI and lifelong services.

If you want inspiration, advice and knowledge for planning your future campaigning the guide provides evidence and resources specific to campaigning on CI provision.

To access the guide visit:
www.ciicanet.org/resources

“
You already have the most important and valuable tool you need: your story. By translating those experiences to policymakers, you can play a critical role in shaping legislation and policy for families, consumers, and the medical community.

ACI Advocacy Guide

Authors: Sue Archbold, PhD, Brian Lamb OBE, 2024

This resource was supported by an educational grant from Cochlear.

www.ciicanet.org



CIICA has launched a new Advocacy Guide to increase access and support for CI services. during their Advocacy conference in Brussels to support CI users and campaigners. The guide was welcomed at the conference by campaigners as helping to support their capacity to make their voice heard.

The guide aims to support user and family advocates, professionals and all those campaigning to improve aspects of CI access and provision of services. It is based on a series of case studies of successful campaigns, many undertaken by CIICA members, to help advocates think about what would be relevant to their own activities.

It also outlines an overall plan for improving CI provision and links to other examples, resources and advice for advocates. With this guide, CIICA wants to encourage unified voices and action to increase access to CI and lifelong services.

Current advances in access to CI and support services have only happened because of

the energetic and persistent advocacy and campaigning of user groups and individuals locally, supported by committed professionals and industry. This guide aims to help them build on those successes and break new ground in ensuring provision and support are available to all who need it.

If you want inspiration, advice and knowledge for planning your future campaigning, the guide provides evidence and resources specific to campaigning on CI provision.

“You already have the most important and valuable tool you need: your story....By translating those experiences to policymakers, you can play a critical role in shaping legislation and policy for families, consumers, and the medical community.”
(American CI Alliance, Advocacy Guide)

To access the guide go to <https://ciicanet.org/resources/a-practical-guide-for-ci-advocacy/>

EURO-CIU is a founding member of CIICA.

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[FINLAND – The Finnish Federation of the Hard of Hearing \(FFHOF\) –
Welcome to the Nordic Summer Days for Deafened in Kuopio](#)



The Finnish Hearing Association is organizing the [Nordic Summer Days for Deafened](#) from 31 July to 4 August 2024 at the Rauhalampi Spa Hotel, located on the beautiful shore of the lake Kallavesi, 5 km from the centre of Kuopio.

On Wednesday there will be arrival in the afternoon/evening, information and "Happened since last time" reports from the different participating countries.

On Thursday the programme will include a presentation of updates on CI surgery. After this, we will take a lunch cruise on the lake Kallavesi and in the afternoon there will be an opportunity to participate in a Craft workshop. In the evening, we have a programme organized by hotel Rauhalampi: we will get acquainted with traditions of province Savo and have the opportunity to go to a smoke sauna.

On Friday we will have a full day excursion to Koli National Park.

On Saturday we get to hear a presentation about an Evidence-based specialised rehabilitation programme based on cognitive behavioural therapy (CBT) for management of disturbing tinnitus. Then we will explore the sights and city centre of Kuopio.

Summer days end on Sunday after breakfast.

The final date of Registration has now passed. If you have any questions, please contact Ms. Tarja Kaikkonen at tarja.kaikkonen@kuuloliitto.fi. Further information about the Summer Days will be sent to those who have registered.

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THE NETHERLANDS – OPCl – Report of the OPCl Contact Day in Nijkerk 9 March 2024



Photos – (clockwise from top-left) - Henk van Rees & Ingrid Cuppen (organisers of the day), Jan Willem Wasmann, opening of the day by Hennie Epping, Prof Johan Frijns, lunch, Prof Johan Frijns, and Alexander Wong & Mariska Stam

Setting up and welcome

A little after ten o'clock, I walked into De Schakel. Some volunteers had already set up the rooms for our OPCI Contact Day and the exhibitors had set up their tables. The registration table was also ready to receive our visitors.

By 10:30 am, visitors were trickling in. In all, there were 150 visitors – the maximum number – and volunteers.

Theme

Hennie Epping, president of OPCI, opened the day at 11 o'clock and then Ingrid Cuppen and Henk van Rees explained the programme.

The theme of the day was Innovation within CI care. The programme consisted of a lecture and quite a few workshops. A lecture by Prof Johan Frijns of LUMC Leiden, a workshop by Jan-Willem Wasmann of Radboud Hospital, a workshop by Mariska Stam of Zorginstituut Nederland and workshops by three CI manufacturers. The workshops were held both in the morning and in the afternoon so that everyone could attend each workshop.

Innovation CI care by Prof Frijns

Professor Frijns is professor of ENT at LUMC Leiden. He talked about the future of the CI and what we can (possibly) expect.

In 1988, he started a clinical programme in Leiden for rare ear diseases, which included CI. Fundamental research was carried out, which CI care uses.

Frijns talked about the eligibility criteria for a CI. Previously, you had to be profoundly deaf, but nowadays the criteria have been raised slightly. He gave the message to start a CI course on time and avoid losing your job. Socially, Frijns had not only looked at what it means for the patient, but also for society. "Hopefully with this we can motivate the government to widely reimburse CI because it makes money for B.V. Netherlands," he said.

The CIs are good and special aids, but have limitations.

- Limited speech understanding in background noise.

Especially in noisy conditions, you often cannot keep up, which then limits your ability to function at school and at work. Hard work is being done on this.

- Poor directional hearing.

Directional hearing with one good ear is difficult. You need two ears to hear direction properly. With a hearing aid on the other side, things go better, but not optimally. Nor is it optimal with 2 CIs. You can and cannot encode certain information with CIs. That too is being worked on.

- Poor perception of music.

There are CI wearers who enjoy music, but there are also CI wearers who find music downright out of tune. Music is really 'a thing' with CI.

Workshop by Jan-Willem Wasmann (audiologist Radboud Hospital Nijmegen)

Jan Willem Wasmann is an audiologist at the Radboud Hospital in Nijmegen. He gave an interactive workshop on barriers, wishes, but also opportunities around 'remote care', or remote support.

By 'remote care' one thinks of hearing tests, questions and problems, preparation for a new processor and remote explanations. But fitting, setting programmes and adjustment

of hearing aids and CIs can also be done remotely.

First, participants complete a questionnaire on whether they prefer 'remote care' or 'connected care', meaning care close to the patient in the clinic.

There are those who prefer 'remote care' to going to the clinic. Many would rather solve problems themselves than go to the clinic for every problem, but travel time is also one of their reasons.

There are also people who prefer to go to the clinic. One reason is that these people are afraid of upsetting or breaking equipment. Also, these people prefer to go to the clinic because of human contact.

Discussing remote and clinic support for a while, Wasmann also talked a little about how 'remote care' works and what developments there are. Finally, some attendees asked questions.

Workshop by Mariska Stam and Alexander Wong of the Care Institute of the Netherlands

Mariska Stam is project manager of the Care Institute of the Netherlands and Alexander Wong is a colleague of hers. They told us about the approach in projects of hearing care, including CI and hearing aid care. The themes of this workshop are integrated care, hearing aids and education.

The Care Institute's role is to promote quality, affordability and accessibility of care. It does this by identifying opportunities and innovations and discussing improvement proposals with parties. However, the Care Institute does not make laws and regulations. Those come from the Ministry of Health.

Hearing care has three components:

1. Technical compensation, i.e. a hearing aid, CI or other hearing aid.
2. Communication training, including speech perception, gestures and communication strategies.
3. Psychosocial support. In this, people are coached in accepting hearing loss, how to function with hearing impairment, entering into and maintaining relationships and coping with stress and fatigue.

For hearing care at the policy level, several projects are already under way. The Healthcare Institute assesses whether a certain treatment for a certain indication meets the state of science and practice. This is a legal criterion to determine which care is still insured in the Netherlands. If care is not proven effective, it does not belong in a basic package. For CI the Care Institute has also done those assessments, contributing to CI care in the Netherlands.

Lunch break

During the lunch break, participants had a long and ample opportunity to visit the booths and get information from the manufacturers of CIs, or assistive devices.

The company Sennheiser, presented a support system currently running in De Schakel, a successor to the loop.

And, of course, people had the opportunity to interact with each other.

After the lunch break came a few more presentations, namely the visit of the workshop that people could not attend in the morning and the workshops by the three CI manufacturers.

Workshops by three manufacturers

Visitors attended the workshop by the manufacturer from whom they wear their CI.

The manufacturers told what innovation looks like in practice and what to expect in the (near) future.

To conclude

At the end of the programme, Ingrid Cuppen and Henk van Rees, organisers of the OPCl Contact Day, summarised the three workshops.

Hennie Epping then closed the meeting by thanking all those present, the speakers, the exhibitors, the staff of De Schakel and the volunteers. Special thanks were given to the interpreters. Without their input, it would probably have been very limited or not possible for many to experience this day.

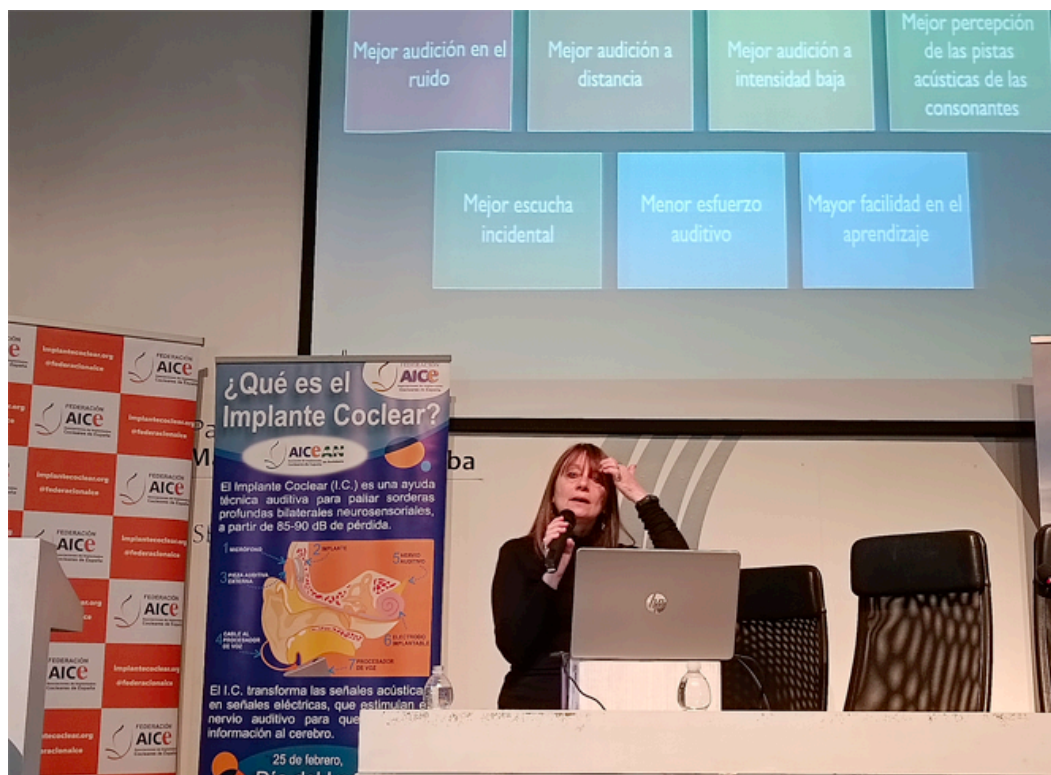
Afterwards, there was an opportunity for a final chat over a drink or to visit or chat with the exhibitors.

With this, OPCl looks back on a very successful day.

Wies Groeneveld

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[SPAIN – AICE – Auditory-Verbal Therapy \(Re\)habilitation Course \(AVT\)](#)



In January, Seville hosted an “update” event on Auditory-Verbal Therapy (AVT) organized by the Federation AICE. During the course, key questions were raised about the need for auditory therapy for children with hearing devices from an early age, the role of parents and adjustments in the working approach of therapists. Hilda Furmanski highlighted the technological evolution that allows profoundly deaf children to develop auditory and language skills but stressed the importance of identifying specific differences in each case to improve communication and learning.

Topics such as classroom acoustics and the use of amplification systems to improve hearing and reduce auditory fatigue were addressed. These aspects were discussed in a round table moderated by Inmaculada Soto, president of AICEAN. The discussion focused on the challenges faced by professionals in schools when caring for students with

cochlear implants, generating an enriching debate among attendees and sharing experiences on educational and therapeutic intervention for children with hearing loss.

The organization of work programmes for children with hearing loss was also discussed, highlighting the importance of having clear objectives rather than accumulating didactic material. Hilda emphasized the need for family involvement in AVT, stressing that parents must be informed and actively involved to ensure therapeutic success. The more than 100 speech-language pathologists present reviewed the functional scales of auditory development and intervention in cases of unilateral hearing loss. The day concluded with a presentation of current therapeutic strategies and a review of evidence-based information, providing attendees with tools and knowledge to improve the aural rehabilitation of children.

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[SPAIN – AICE – IX Solidarity Race for Cochlear Implants](#)



In March, the IX Solidarity Race for Cochlear Implants took place in Albacete. This year with a participation of 300 people. Among the attendees was the Mayor Manuel Serrano, who ran the race himself, as well as councillors of local political parties and members of the Provincial Council of Albacete. Prizes were awarded to the three winners of the female and male groups and the participants in wheelchairs with reduced mobility. Thank you all for your great effort, you are true champions!

The cochlear implant solidarity race has become an annual tradition in Albacete. This event not only promotes the importance of cochlear implants to improve the quality of life of people with hearing loss, but also encourages solidarity and community support. Participants, coming from various parts of the region, unite in a day full of enthusiasm and commitment, running for a noble cause that seeks to raise awareness of the benefits of

this technology. The race has become a symbol of hope and collaboration.

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[SPAIN – AICE – The cochlear implant sign](#)



Photo: Laia Zamora demonstrating the sign for a cochlear implant

In 2002, the Spanish Federation of Cochlear Implant Associations (AICE), suggested the adoption of a preferred sign for CI, because they found that some CI users were offended by the “electric ear/head” sign used in, for example, ASL, AUSLAN and BSL.

This fact was communicated to all associations of the Signing Deaf Community as well as to the media.

During the 6th European Congress on Paediatric Cochlear Implantation held in February 2002 in the Canary Islands, it was presented to the world scientific community.

Numerous representatives from American countries were interested in the subject and decided to propose its adoption in their respective countries.

AICE, as the Spanish representative in the European Association of Cochlear Implant Users, proposed at the EURO-CIU Assembly in Amsterdam in April 2002, the adoption, by all European cochlear implant users' associations, of the same sign to identify the cochlear implant.

The thumb and forefinger join together to form the cochlear implant magnet and the other three fingers indicate the information/sound flowing into the device.

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[TURKEY – Activities organized by Biyonik Kulaklı Çocuklar Derneği \(the Association of Children with Bionic Ears\) between February and May 2024](#)

5. Mr. Oğuzhan Ceran, the vice president of our association, visited our ENT doctors at Etlik City Hospital and gave information about the activities our association has done, and the activities planned to be carried out.

6. Afyonkarahisar provincial representative of our sixth association, Müge Açıkgöz Orhan and her son, bilateral bionic ear user Ahmed Akif, visited the governor of Afyonkarahisar, Associate Professor Kübra Güran Yiğitbaşı, in her office. He gave information about the bionic ear and our association. Our association's book, 'Journey to the Voices with Naz', was presented to him as a gift.

7. We attended the Vefa (Fidelity) award ceremony organized by Astop. Vefa (Fidelity) awards, which are held every year in April, were held on April 2, 2024. As the Association of Children with Bionic Ears, we gave our Vefa (Fidelity) award to our ear, nose and throat doctor Levent Ongun, who has given voice to more than three thousand patients in his professional life.

8. Ata Çankır, Alperen Korkmaz and Ezgi Karakaya, young people of the Bionic Kukali Kids Association, talked about the high school entrance exam (LGS) process by broadcasting live on Instagram. They also reminded us of the additional rights granted to disabled people.

9. The second spring symposium of Capital University was held under the leadership of Asuman Alnıaçık, assistant professor, head of the audiology department of Başkent University, and with the participation of professors from different universities and companies. The vice president of our association, Mr. Oğuzhan Ceran, and our board member, Mr. Sinan Tarkan Aslan, participated.

10. A live broadcast was broadcast on Instagram on May 13, 2024, moderated by our Burdur provincial representative Elif Çetintav. The guests of the live broadcast were President Ali Ümit Pamuk, members Vahide Semen and Halime Ceren Tepeli from the youth committee team of the Association of Children with Bionic Ears. The live broadcast topic was about the week of disabled people.

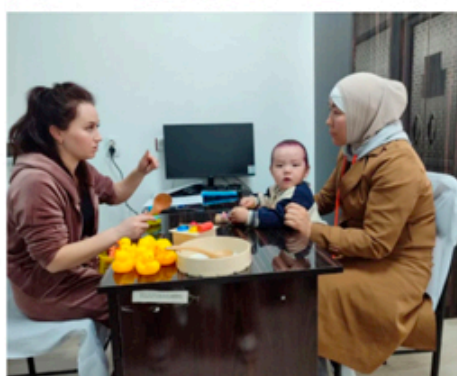
11. Our children with bionic ears participated in the theatre project of which we are partners, and the performance started at Ankara Farabi Stage on May 11, 2024.

12. In the first week of June, we are meeting with families in Mardin, one of the easternmost provinces of Turkey, with the best doctors, audiologists and hearing teachers in their fields. Our aim is to inform families and help the rehabilitation centres there with their shortcomings.

13. Our association will hold a management meeting in mid-summer. All our representatives will attend the meeting in Ankara, and we will discuss the feedback about the activities we have carried out. We will brainstorm for our future projects.

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[THE LEHNHARDT FOUNDATION – KYRGYZSTAN – supporting the development of a sustainable programme for the treatment of hearing impaired/deaf children in Kyrgyzstan to facilitate their inclusion in general educational institutions.](#)



The number of children with CI in Kyrgyzstan is continuously increasing, based on charity programmes of various countries, institutions and private individuals. Unfortunately, many of the donors focus on purchasing the cochlear implants and having the operations carried out free of charge by foreign surgeons.

According to our experts in Western Europe, many of the children are already relatively old

at the time of operation, since until recently neonatal hearing screening and therefore early detection did not exist in Kyrgyzstan.

These children in particular would require more post-operative care and intensive rehabilitation than children who received their CI before the age of one year. This is also not offered yet.

These children's chances of being included in mainstream educational institutions are poor because local therapists and teachers at mainstream educational institutions lack knowledge of how to support them in their development.

Therefore, after completing two projects – on the topics of "Cochlear Implantation" and "Neonatal Hearing Screening" in 2020 – 2023 – we decided to submit a new project to the German Society for International Cooperation (GIZ). It was approved and started on April 1st of this year. We were able to identify competent and committed partners in Kyrgyzstan:

Kelechek Rehabilitation Centre, Uplift (NGO), "Slyshim Vmeste" ("Hear together" parents' association) and IAHRs (International Association of Hearing Rehabilitation Specialists).

In Germany we were able to win as supporters of our project:

Landesbildungszentrum für Hörgeschädigte in Osnabrück, Niedersachsen (State Educational Centre for Hearing Impaired) and CIC Rhein-Main in Friedberg, Hessen (Cochlear Implant Centre Rhein-Main).

The main components of this project are:

- Internship Opportunities: We will arrange internships for sixteen therapists from various regions of Kyrgyzstan to provide them with valuable hands-on experience.
- Training Sessions: Comprehensive online and offline training sessions will impart skills and knowledge to professionals, which they need to support individuals with hearing impairments effectively.
- Provision of information material in local languages: Documents and materials will be translated into Russian and Kyrgyz languages to ensure wider accessibility, fostering better understanding and engagement among local communities.

Dr. Monika Lehnhardt-Gorany

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[THE LEHNHARDT FOUNDATION – CIICA Conference in Brussels](#)



As part of our initiatives, Asel – president of the parents organization “Hear Together”, an ENT doctor, and mother of two children with cochlear implants – participated in the “CI Advocacy in Action: First Global Conference” organized by CIICA in Brussels in May 2024.

The **Lehnhardt Foundation** invited two other mothers of children with cochlear implants – Lusine from Armenia and Nataliia from the Ukraine to join the event.

All three found participation in this conference very valuable and contributed actively. Lusine emphasized the importance of parental involvement in the cochlear implantation process, while Nataliia highlighted the diverse opportunities that life with cochlear implants offers. Their stories testify to the paramount importance of the commitment of individuals and coordinated initiatives.

Here are their comments:

“During the event, I noted several key points that I believe will be beneficial in my country. However, the most valuable aspect for me was the opportunity to interact with successful cochlear implant users, as well as active parents and representatives of various organizations supporting CI users. This was truly inspiring and motivating for me to continue my work in this field.” – Asel, Bishkek

“Listening to those people, talking to them, and seeing the results of their work, I realized that as parents, we still have a lot to do. Yes, doctors, speech educators, and the Armenian International Medical Foundation are doing a great job in Armenia for cochlear implant users. However, parents' involvement in this process should be more significant.”

– Lusine, Yerevan

"The direct face-to-face exchange was particularly valuable and enriching. The multitude of interesting lectures and discussions opened up new perspectives for me and inspired me. This conference gave me a new perspective on the diverse possibilities and opportunities that life with cochlear implants offers." – Nataliaia, Lüneburg, refugee from the Ukraine

This project, which aims to improve opportunities for inclusion for children with CI, will last for two years and we will continue to report on its hopefully successful progress.

Dr. Monika Lehnhardt-Gorany

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[RELATED CONGRESS – C12024 International – 10 to 13 July 2024](#)



We are excited to be leading the charge for the 2024 American Cochlear Implant Alliance CI meeting, set amidst the vibrant international backdrop of Vancouver, British Columbia, in July 2024. As the planning of this extraordinary gathering unfolds, it's evident that collaboration knows no borders. Not only within the realm of cochlear implantation care, but also in planning this event with a number of Canadian leaders that promises to be enlightening, empowering, and transcendent for all who attend.

Beyond the exchange of knowledge and expertise, we recognize the insights and riveting discussions. The CI Conference Program Committee has meticulously curated seven key themes that lie at the current core of cochlear implantation for both adults and children. These themes reflect the dynamic and evolving landscape of auditory science:

1. Successful Pathways to Cochlear Implantation: A Global Perspective.
2. Effects of the COVID Pandemic on Cochlear Implant Outcomes.
3. Listening Impacts on Literacy and Learning in Children with Cochlear Implants.
4. Socio-emotional Health in Cochlear Implant Users.
5. Cochlear Implantation in Single Sided Deafness for Adults and Children: Candidacy, Provision, and Outcomes.
6. Cochlear Implantation Provision at Both Ends of the Age Spectrum.
7. Optimized models for cochlear implant workflow.

[Click here for further details on the conference website.](#)

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[RELATED CONGRESS – Management of the Tinnitus & Hyperacusis Patient – 8 & 9 August 2024 \(In-person & remotely\) for professionals and patients](#)

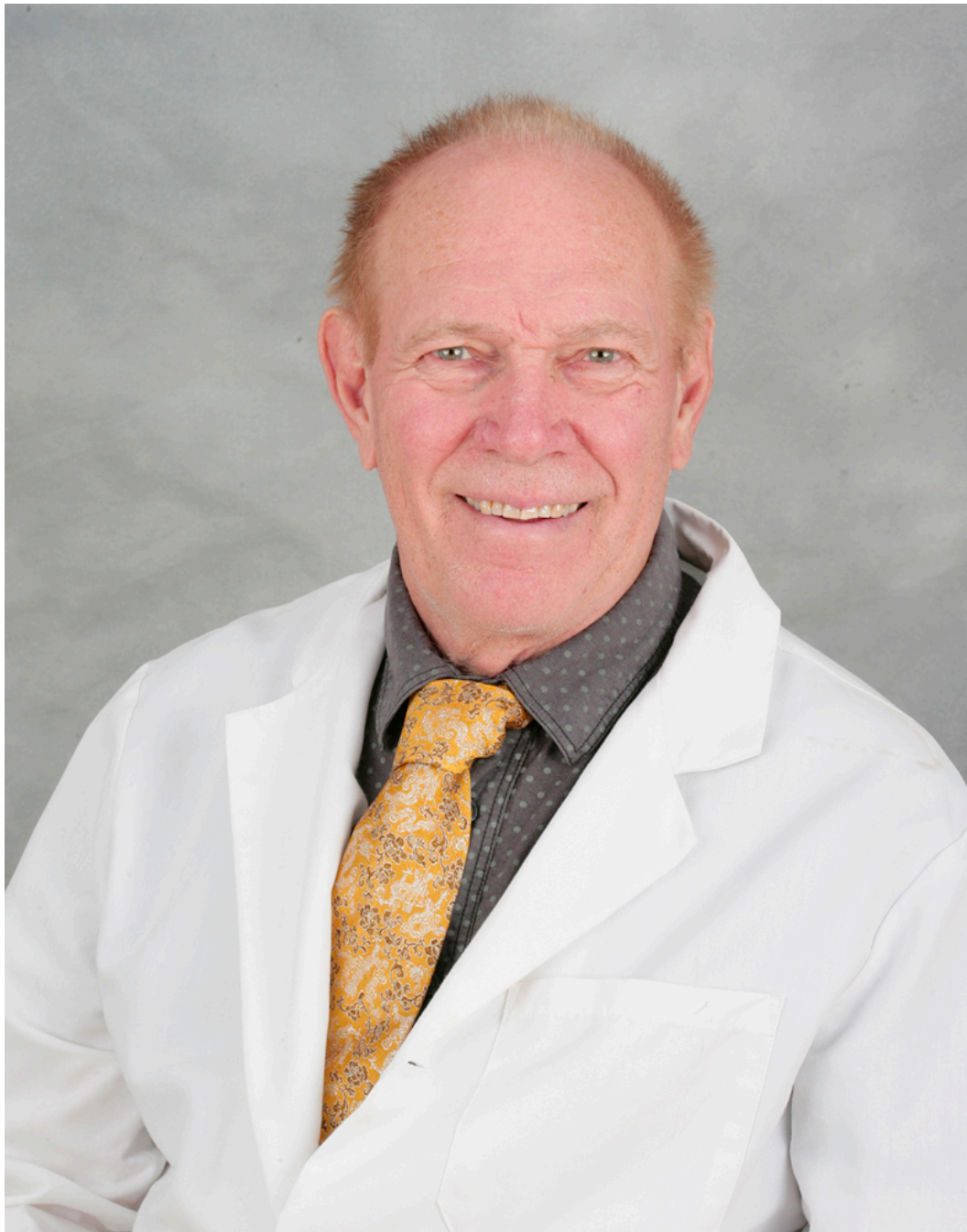


Photo – Prof Rich Tyler

The University of Iowa, USA, Department of Otolaryngology–Head and Neck Surgery; Communication Sciences-Disorders

Now in its 31st year, the Management of the Tinnitus and Hyperacusis Patient is offered in live and remote modalities. Professor Rich Tyler, Department of Communication Sciences and Disorders, directs the conference. [Click here for venue.](#)

The option to attend virtually is on the [registration page](#). The price is the same to attend in-person or virtually. An email with a link to attend virtually will be sent the week of the conference.

There will be a presentation on CIs for tinnitus, and several European presenters. [Click here for list of speakers.](#)

Intended Audience and Purpose

Invited presenters are from around the world, and focus on understanding the mechanisms, and understanding the problems of hearing, sleep, concentration, and

thoughts/emotions. Updates on in-person and remote counseling are reviewed from different perspectives. Companies explain and demonstrate their latest approaches for wearables. New approaches and research needs are discussed.

The conference is important because it brings together researchers, clinicians and people suffering. They each learn from the others perspective. Researchers better understand the needs. Clinicians are exposed to other novel helping approaches. People suffering learn about others experiencing similar issues and view the variety of approaches and how different clinicians and researchers with different backgrounds interact in an attempt to move the field forward.

Guest of Honor

Kelly Jahn, Au.D., Ph.D.

Audiological Evaluation of Hyperacusis: Current Challenges and New Directions

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RELATED CONGRESS – European Academy of Otolology and Neurotology (EAONO) – 4 to 7 September 2024



After the well-organized virtual EAONO meeting in London in 2021, we would like to welcome you to the 2024 face-to-face EAONO workshop which will be organized from 4th to 7th September in the oldest city of the Netherlands; Nijmegen. The beautiful and historically rich city of Nijmegen is located in the east of the Netherlands near the German border. A large percentage of the inhabitants of the city are in their 20's due to the number of schools and universities located there. The conference venue will be Concertgebouw de Vereeniging, a concert hall officially opened in 1915 and built in a mixture of Art Nouveau and Art Deco styles.

We are looking forward to a scientific program with state-of-the-art lectures, scientific presentations and discussions. Moreover, there will be ample opportunity to submit and present original papers.

[Please check out the website by clicking here.](#)

The Programme has now been published – [click here](#).

Looking forward to welcoming you! On behalf of the organizing committee:

Jef Mulder and Myrthe Hol

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RELATED CONGRESS – The 36th World Congress of Audiology – Paris –

19 to 22 September 2024: a bird's eye view on what matters most in Audiology

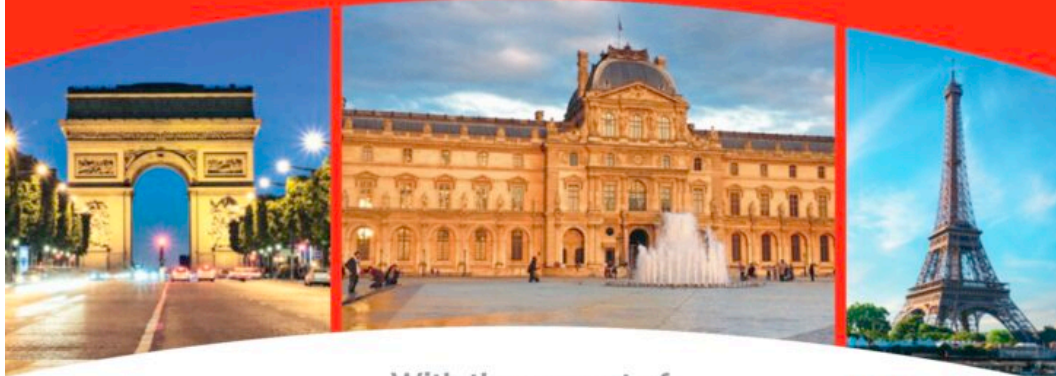
Preliminary programme

For an updated version of the program please scan the QR code



Save the date | **19, 22 September 2024**

Paris, France
CNIT Paris La Défense



With the support of



The 36th World Congress of Audiology is coming up and it is in Paris, from the 19 to 22 of September 2024 50 years almost to the day since it last came to France!

The French Society of Audiology, with the support of the French Society of Otorhinolaryngology, has been working hard to bring together the world's leading experts in hearing loss, tinnitus and vestibular disorders for a scientific conference that will be remembered.

From Teleaudiology to the emergence of Artificial Intelligence, from the specificities of Hearing Aid delivery and Audiological services across the globe to the practice of Evidence-Based audiology, all of the profound upheavals that span our professional practices will be addressed. In this respect, the three themes chosen for the 2024

roundtables promise valuable exchanges with the opinion leaders concerned, these topics being: Hearing & Cognition, Hearing & Neurodevelopmental disorders, and Ototoxicity.

Because their cutting-edge expertise is inseparable from the lightning progress made in our discipline, Paris 2024 will also be a choice forum for researchers in Auditory Neuroscience, Genetics, as well as Speech, Language and Hearing disorders. We, of course, will not overlook the undeniable contribution of Imaging to the diagnosis of inner ear pathologies, whether they affect the function of hearing or balance.

Last but not least, therapeutic and industrial innovations will be highlighted in order to promote the outcomes of clinical and translational research.

Our ambition is to offer audiologists from all over the world an acute insight into the emerging pathologies in Audiology and Otoneurology through outstanding keynotes and numerous practical workshops where seasoned specialists as well as promising young professionals in training will be able to come together to share their experience or deepen their knowledge.

In 2024, the eyes of the world will be on Paris, and not only for the Olympic Games. So start preparing your trip now, we are looking forward to welcoming you to the French capital for an unforgettable event!

***For the French Society of Audiology,
Prof. Hung THAI-VAN, M.D. Ph.D.
President of the 36th World Congress of Audiology***

(Note: Speakers include CIICA, of which EURO-CIU is a founder member)

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RELATED CONGRESS – ESPCI 2025 – 11 to 14 June 2025 – Only one year to go!



It is a pleasure and great honour to host on behalf of the Hannover Medical School, Department of Otolaryngology, the European Symposium on Paediatric Cochlear Implantation 2025 in Hannover.

We are very honoured to host the important European Symposium on Paediatric Cochlear Implantation 2025 again in Hannover after the first event in 1996. It will be possible to demonstrate the fast development over these three decades with the enormous impact on the life of deaf children and their families, but also the change that has happened in the

field of teaching, rehabilitation, diagnosis and concepts of care with the buildup of networks of multidisciplinary inter-institutional networks.

We will focus on well-selected topics presented by keynote speeches and focus sessions, educational sessions, training workshops and a large industry and scientific exhibition.

We are looking forward to meeting you at ESPCI 2025!

Committee ESPCI 2025

Organizing committee

- Thomas Lenarz
- Andreas Büchner
- PD Dr. Angelika Illg
- Andrej Kral
- Hannes Maier
- Waldo Nogueira

Scientific committee

- Samuel John
- Prof. Anke Lesinski-Schiedat
- Prof. Gerritt Paasche
- PD Dr. Nils Prenzler
- Dr. Thomas Rau
- Dr. Rolf Salcher
- PD Dr. Verena Scheper
- Dr. Max-Eike Timm
- Prof. Athanasia Warnecke

Don't forget to visit the [website](#) for more information.

Stay tuned with our newsletter and socials as we are soon introducing the first keynote speakers to you.

Congress secretariat, Europalaan 16, 's-Hertogenbosch, Noord-Brabant 5232 BC, Nederland, +31(0)73 690 14 15

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RELATED CONGRESS – International Symposium on Usher Syndrome – 19 to 21 June 2025



On 19, 20 and 21 June 2025, the International Symposium on Usher Syndrome will take place in Nijmegen (NL) USH2025.

Please save the date!

Knowledge sharing, cross-pollination and meeting each other are important goals of the scientific conference on the Thursday and Friday. At USH2025 Congrestival (Saturday), appealing contributions and stories from the first two days will be shared with the USH

Community (people with Usher Syndrome, their families and loved ones).

We also make USH2025 Congrestival a positive and inspiring Festival of the Senses. People with and without Usher Syndrome then have the same sensory stimulating experience. A unique experience for everyone.

More details to come, please share widely with your networks and in your communication, thank you!

<https://www.ussh2025.org/>

Best regards,

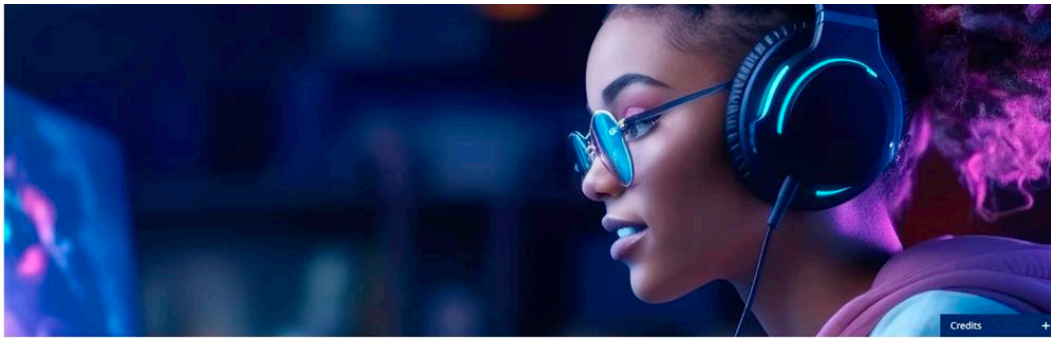
Dominique Sturz

Patient Advocate Usher Syndrome & Rare Diseases Usher Initiative Austria

usher-syndrome@gmx.at

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[WORLD NEWS – Shaping the future of safe listening in video gameplay and esports: web meeting](#)



More than 3 billion gameplay and esports enthusiasts worldwide are at risk of hearing damage and sound-induced hearing loss. In recognition of this, the International Telecommunication Union (ITU) and the World Health Organization (WHO) Ear and Hearing Care Programme are working together to develop a technical standard for safe listening in video gameplay and esports. This initiative aims to create the world's first Global standard for safe listening in video gameplay activities. After a series of technical workshops, the draft standard is now in a mature format.

The WHO Ear and Hearing Care Programme is hosting an online meeting entitled Shaping the Future of safe listening in video gameplay and esports to share the status of the draft with all stakeholders and provide an opportunity for discussion.

You are kindly invited to join the online meeting on 26 June, 2024 at 2:00PM (CEST).

[Please register here.](#)

Closed captioning in all 6 UN languages will be available during the web meeting.

For more information, please visit the [event page](#) or write to us at mls@who.int

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[WORLD NEWS – Calling for a European Hearing Health Strategy](#)



The Hearing Health Forum EU (HHFEU) is proud to announce its Manifesto advocating for the European Commission to initiate a European Hearing Health Strategy. Hearing health policies across EU member states are rare, increasing the detrimental health and socio-economic effects of untreated hearing loss. A European Hearing Health Strategy would increase awareness, improve prevention at a national level, enhance access to hearing care, and support research for informed policy-making.

EURO-CIU's role within Hearing Health Forum EU

With Robert Mandara being the President of the EURO-CIU, he also represents the needs of cochlear implant users and EURO-CIU member organisations within the HHFEU. The HHFEU is an alliance dedicated to raising awareness of hearing loss and improving access to hearing devices, such as cochlear implants and assistive technology, for the 196 million Europeans living with hearing loss. The collaborative features hearing health organizations such as **EURO-CIU**, **HEARRING Group**, and **MED-EL**, chaired by Member of the European Parliament **Agius Saliba**.

Your Signature Matters

EURO-CIU fully supports and has proudly endorsed the Policy Manifesto.

To read and endorse the Manifesto, visit hearinghealth.eu/hearing-manifesto. Follow the **HHFEU's LinkedIn page** to not miss any updates or content related to the Policy Manifesto.

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[WORLD NEWS – World Hearing Forum](#)



The World Hearing Forum, with over 200 members, drives a global advocacy initiative that provides a common platform and narrative for all stakeholders to collaborate and raise awareness about the need and means for ear and hearing care through its five workstreams:

1. Make Listening Safe,
2. World Hearing Day,
3. Changemakers
4. External Relations and
5. Members Engagement, to achieve its advocacy goal.

Interested in becoming a member? The membership application process will be open from August 15 to October 15, 2024.

[Click here](#) for more information and to join.

Highlights from World Hearing Day 2024

As in the past years, the largest advocacy event for ear and hearing care took place on March 3. We want to take this opportunity to reflect on the World Hearing Day 2024 and share with you some of the highlights from your campaign efforts.

World Hearing Day 2024 focused on overcoming the challenges posed by societal misperceptions and stigmatizing mindsets through awareness-raising and information-sharing, targeted at the public and health care providers. This year a total of 688 events were registered.

This year is a way to draw attention to the positive impact of timely identification and different options of rehabilitation of ear and hearing problems, a **Changemakers photo exhibition** took place at WHO, HQ in Geneva as well as virtually.

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WORLD NEWS – AUSTRIA – Structured telephone training in cochlear implant users



EXCELLENCE dedicated to HEARING IMPLANTS

The HEARING Group is an independent network of world-leading experts and centres concerned with all aspects of hearing restoration and implantable hearing devices. Through being comprehensive, co-active, innovative, and educational they are committed to making progress every day. Detailed information on the HEARING clinics, their goals, and members can be found on the HEARING website (<https://www.hearing.com/>).

In recent years, telephone use in the private setting has become considerably easier for cochlear implant users thanks to the emergence of smart phones which initiated the era of video calls. However, phone calls with administrative authorities and health care providers are mostly voice-only, which may constitute a challenge to people with a cochlear implant. In these cases, proper preparation right before the phone call, including a list of the topics to be covered and relevant vocabulary, is recommended.

In the long run, a structured telephone training may help increase the ease and the quality of voice-only telephone communication in cochlear implant users besides advanced auditory training. Giles et al (2005) (1) published the first therapy guidelines structured in a hierarchical manner from the easiest to the most difficult listening situations on the phone. The guidelines cover properly positioning the telephone receiver, discriminating between different ringing tones, practicing phrases typically used in telephone conversations, practicing repair strategies (such as asking for repetition), dealing with open-set questions, and also coping with background noise. Moreover, it is also important to boost the cochlear implant user's confidence and increase their assertiveness when talking on the phone (2). Audiologists recommend consulting rehabilitation experts for effective telephone training tips (3).

A couple of studies provided evidence of the effectiveness of structured telephone training. Mathur et al. (2015) (4), for instance, showed that a 6-month telephone training in prelingually deafened children with a cochlear implant provided by professionals clearly improved the children's telephone skills. Ideally, telephone training is additionally provided by the parents at home to round off the therapy program as shown by Ihler et al. (2017) (5).

Newly developed streaming tools can directly transmit language or music from smartphones or TV sets to the new-generation audio processors. This will also help simplify telephone conversations with a cochlear implant in the future.

Prof. Dr. Wolf-Dieter Baumgartner
General Secretary

References:

- (1) Giles, E. (2005). Telephone training with a cochlear implant. In Pedley, K., Giles, E., & Hogan, A. (Eds.) Adult cochlear implant rehabilitation (pp. 219-244), London: Whurr.
- (2) <https://blog.medel.com/tips-tricks/tips-tricks-for-adults/telephone-tips-for-cochlear-implant-recipients/>
- (3) <https://www.medel.com/support/rehabilitation/rehabilitation-downloads?itemTitleKey=telephone+training>
- (4) Mathur K, Jeyaraman J, Mathur MC, et al. (2015). Structured telephone training improves telephone competence in prelingually deafened children with a cochlear implant. Cochlear Implants Int, 16(5):262-9.
- (5) Ihler F, Blum J, Steinmetz G, et al. (2017). Development of a home-based auditory training to improve speech recognition on the telephone for patients with cochlear implants: A randomized trial. Clinical Otolaryngology, 42(6):1303-1310.

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**WORLD NEWS – FINLAND – Honorary Doctorate Conferment
Celebrations at University of Oulu, Northern Finland, May 2024**



I will highlight some moments over the three-day honorary doctorate conferment celebrations in Oulu, the north of Finland. As stated on the University of Oulu website: “An honorary doctorate is the highest honour that the University can confer to a person. The University has invited persons for conferment, who have distinguished themselves on the fields of science represented in the University of Oulu.” (University of Oulu, 2024).

On the first day, the sword-whetting was challenging for me as a blind person. Yet, I managed to sharpen my sword with Riitta, my companion, on the champagne-wetted grindstone. That seemed like a big waste. We seventeen honorary doctors had a cocktail evening after the sword-whetting. This was the first opportunity to meet the other honorary doctors including the President of Iceland, a Nobel Prize winner for genetics and a film director.

The next morning started off in our full regalia, tails and doctoral hats later. First the rehearsals, followed by a quick cocktail lunch. Then it was time for the actual ceremony. It took three hours with six hundred people.

There were eight faculties, with my faculty Education and Psychology being the last one. Apparently when I came on stage with Riitta, my wife, and one of my interpreters, the audience went quiet as something different was about to happen! Who is this blind honorary doctor with a white cane? The moment I got the hat, sword and diploma was very emotional as I realised that all my work got its recognition. Quite overwhelming.

Next, we had the procession through the city, which was quite extraordinary because I was leading it with Riitta and my two interpreters, along with the other honorary and young doctors. And at the end, the invited guests, including my brother and his wife. There were so many people with cameras I felt like a celebrity. Then Riitta said: "Look, there are deaf people signing to you!" So, I signed back: "Thank you for coming!"

After the procession we went to the cathedral for the special thanksgiving service. Getting into the cathedral was tricky: walking up steps with the sword in one hand, the hat in the other and Riitta guiding me. The service was very moving with several languages and music styles.

A quick change back at the hotel and back to the university for the banquet and ball, with yet more cocktails! The ball included traditional dances which was challenging but fun to do. We stayed until the wee small hours of the morning. Leaving at 3am we heard the bird chorus singing. We only got 4 hours of sleep (well, some of us did) before the boat rowing competition on the final day, again with cocktails and a lunch.

I had to cover my implant to keep it dry from the rain. "I must be mad to be doing this" but went with the flow with Juha as my guide. When I got on the boat, my implant battery ran out. So, I was totally deaf and blind, it was my worst nightmare! No problem, I just followed my interpreter's body movements when he rowed, and it worked fine. It was all fun and light-hearted anyway.

Everybody treated me as equal during these three days. Even the President of Iceland came to me saying, oh, you're Russ Palmer, I've read your most inspiring story! I had lovely discussions with a Nobel Prize winner, a film director and one fascinating one with a professor studying Usher syndrome. All in all, it was a very privileged event.

Dr Russ Palmer

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[WORLD NEWS – ITALY – HeAL 2024 – Hearing Across the Lifespan](#)



Photos – clockwise from top-left: Ferdi Grandori & Sue Archbold at the CIICA Stand; Villa Erba Congress Centre; Brian Lamb & Sue Archbold with Helen Pryce at the CIICA Poster; and Villa Erba Congress Centre.

From the 6th to 8th June, about 350 delegates attended this conference in the delightful setting of Villa Erba Congress Centre, Cernobbio, Lake Como – as always, chaired by Prof Ferdi Grandori, with Co-chairs Dr Sophia E Kramer and Dr Alessia Paglialonga.

This congress is a premier platform showcasing cutting-edge developments in Audiology and related fields. With attendees hailing from over 40 countries, this gathering embodies an international spirit, fostering collaboration and innovation. Distinguished for its inclusive approach, the conference embraced professionals from diverse backgrounds, transcending the boundaries of traditional medical models. This inclusivity sets it apart, offering a holistic perspective on hearing care that extends beyond medical aspects.

HeAL 2024 gave an enriching experience with sessions covering both classic and emerging topics. From Epidemiology to Artificial Intelligence Applications, the agenda was curated to provide insights into the forefront of Audiology and Hearing Care at large. Structured sessions, including symposia and special sessions coordinated by leading clinicians and researchers, offered deep dives into pivotal areas such as Precision Diagnostics and Community-delivered Hearing Care.

Esteemed experts from around the globe delivered keynote lectures, delving into topics ranging from Objective measures in cochlear implantation to the importance of Global Partnerships for Multiple Disabilities and of Hearing Screening and intervention programs for people with intellectual disability in their live environment.

Speakers at the conference included Brian Lamb and Sue Archbold from CIICA. EURO-CIU is a founder member of CIICA.

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WORLD NEWS – ROMANIA – Opportunity for creative young (15-30) CI users

VR

GOVERNUL ROMÂNIEI
MINISTERUL CULTURII

Wave's Imprint

< creativity without borders >



Cultural Project Funded by the Romanian Ministry of Culture



OPEN CALL – registration period: 01.06.2024 – 10.07.2024

We discover, support and promote young talents by offering them personalized virtual showrooms and the necessary resources to create an artistic film! In this way, the public has the opportunity to discover your creative universe through some instruments that are more and more present in the world of art professionals' lives.

This call is for you if:

- You are aged 15-30
- You have with a cochlear implant or hearing aids

- You are fond of visual art

You want to meet talented youth from different parts of the world who share the same passions and interests?

You want to exhibit in a virtual art gallery or get involved in the creation of an artistic film?

“Yes! How can I join it?”

Choose 1 to 5 works of art that best represent you artistically or create one, especially for this occasion!

* Eligible works: drawings, paintings, collage, photography, fashion design, sculpture, ceramic, digital artworks.

Scan or take a photo to highlight them as best as you can. It's important that the photos are clear and well-framed. We recommend size/quality: 3840 x 2160 at 300 dpi.

Specify the following information for each work: the artist's name, age, birthplace, work title, size, and the technique used.

Send all materials and information to the official address: office.waveforme@gmail.com

To get involved in the creation of the artistic film:

Send us an email at office.waveforme@gmail.com with the message “I want to be part of the Wave's Imprint feature film team” and we'll get back to you with all the details. (No fee required)

Deadline for submitting works: July 10, 2024

The results will be announced after July 20. Good Luck!

More information can be found at this link: <https://waveforme.org/uncategorized-ro/open-call-registration-period-01-06-2024-10-07-2024/>

The project is funded by the Romanian Ministry of Culture.

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[WORLD NEWS – UK – Auditory Verbal UK \(AVUK\) – New UK research reveals lack of awareness of what deaf children can achieve](#)



(Photo of Ernie Dix)

New research released by charity Auditory Verbal UK has revealed that more than a quarter (28%) of UK adults believe it is not possible for a child born profoundly deaf today to learn to speak as well as a child without hearing loss*.

But with early and effective support deaf children can learn to speak like their hearing peers. Deaf young people like **Ernie Dix (17)**, from London, are challenging these outdated perceptions. Ernie who was diagnosed as profoundly deaf as a baby, is studying film and TV at the London Screen Academy with ambitions to work in the TV or film industry. He was supported to develop his listening and spoken language skills with an Auditory Verbal therapy programme at the charity Auditory Verbal UK when he was a young child.

Ernie's Mum Chrissi explained: *"I didn't think Ernie would ever speak let alone say the word Mum. We are disappointed that years on from Ernie's diagnosis, awareness and expectations for deaf children and young people are still low and that families do not know what options are out there for them."*

Ernie said: *"I have been profoundly deaf since birth and have never felt it has held me back, I think a big part of this is having Auditory Verbal therapy because I have learnt to be a good listener which in turn has helped me access all speech sounds so I speak very clearly and can be understood and I understand others."*

"It is disappointing to hear that 28% of adults believe that children born profoundly deaf cannot learn to speak as well as their peers and even more concerning that so many profoundly deaf children don't have the opportunity to access to Auditory Verbal therapy. Being deaf doesn't define my abilities, it shapes my unique perspective on the world."

The new YouGov* research also shows 85% of UK adults believe Auditory Verbal therapy should be available to all deaf children via publicly funded services (ie, the NHS), while only 2% think it should be paid for privately.*

* YouGov Plc. Total sample size was 2125 adults. Fieldwork was undertaken between 12th – 14th April 2024. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

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[WORLD NEWS – UK – Auditory Verbal UK \(AVUK\) – Calls to next UK](#)



Photo of Hope Dennis and UK Children's Commissioner Dame Rachel de Souza

Hope Dennis (14) a cochlear implant wearer from London joined AVUK Chief Executive Anita Grover and other young people to meet MPs and decision makers in UK Parliament in May (before the UK General Election was called) and share experiences and what matters to them.

Hope, who was born deaf and learnt to listen and talk with Auditory Verbal therapy, joined the All-Party Parliamentary Group for Children and **National Children's Bureau**, along with **Children's Commissioner for England**, Dame Rachel de Souza, to discuss why it is vital to put **#ChildrenAtTheTable**.

Alongside many other young people, Hope shared her experience of growing up in the UK today and what is important to her and joined calls for children to be a priority for decision makers.

Hope called for all deaf children, like her, to have access to early and effective support to develop language and communication. With a general election coming up in the UK on July 4th, AVUK is calling for the next UK Government to be a champion for deaf children and urgently invest in early, effective support for all deaf children, whether they use sign language, spoken language or both, including Auditory Verbal therapy for those families who want their deaf child to learn to listen and talk.

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[WORLD NEWS – UK – Auditory Verbal UK \(AVUK\) – Sharing experiences with CI users, families and professionals and families across Europe](#)



Photo of Auditory Verbal UK graduate Tom Broekhuizen with Auditory Verbal Therapist Mariavittoria Vallarino at MED-EL's event in Scotland

AVUK has been delighted to meet cochlear implant users of all ages, as well as their families, and professionals working with young deaf children at events and conferences around the UK and Europe this month. **Tom**, a Cochlear Implant user, joined Auditory Verbal Therapist Mariavittoria Vallarino at the MED-EL event in Scotland to share his lived experience of cochlear implants and learning to listen and talk with Auditory Verbal therapy.

The 19-year-old film, media and journalism student lost his hearing after contracting meningitis as a baby. He explained: *"I've always accepted being deaf and my cochlear implants as part of me. I have always done the same things as my friends and I'm so proud to be at university now and having worked at summer camp in America last year supporting young people."*

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[WORLD NEWS – UK – Take Our Word For It!](#)



Photos – (Clockwise from top-left) The AVID Language stand at the recent CIICA Conference. Nathan Barlow, audiologist, whose success story features in the book "VOICES of HOPE". The book, "VOICES of HOPE". Tanya's daughters, Onna and Sala, with one of her children's books.

One of the take-aways from the recent (inspirational!) CIICA Conference was this: when it comes to advocating for expanded access to cochlear implants and (re)habilitation support, success stories speak louder than glitzy ads.

That's why I was particularly pleased to showcase the new book from AVID Language, "VOICES of HOPE", for the first time at this conference. Collated by Estelle Gerrett, an experienced Auditory Verbal therapist, this book is a collection of personal accounts, written by parents who have taught their profoundly deaf children to listen (with cochlear implants) and to speak. Each journey is different, reflecting the diversity of deafness, and the families' different cultures and aspirations for their children. The parents describe what it was like at the start, when they did not know what the future held for their children or what might be possible, and how far they have come since those fraught early days. Their stories are inspiring and reassuring, but also open and honest about the obstacles faced along the way.

As Eddie Mukaaya, CIICA Board Member and CI-Dad from Uganda, said in his presentation, "parents are the real deal" in securing successful spoken language outcomes for children with CIs. That's why parent-centred early intervention, such as Auditory Verbal therapy, is so effective (as evidenced in "VOICES of HOPE"), and why it's important to value parental perspectives throughout the CI-process for children, from the initial diagnosis and decision-making through to surgery and (re)habilitation. "VOICES of HOPE" reveals the mindset and rationale of parents who have chosen this path for their children and, as such, is an important read for both newly-diagnosed families who are considering the CI-route (or are early on in their journey) and for the professionals who support them.

"VOICES of HOPE" is the first book for parents and professionals in the AVID Language collection. It joins our bright and colourful collection of books for young children. These books all feature aspirational main characters with hearing loss. The stories are fun and representative, while supporting language development and creating awareness among typically hearing children.

I launched AVID Language when I was teaching my own daughters to speak (I have ten-year old twins: one typically hearing, the other profoundly deaf with bilateral CIs). While I could find plenty of books to support language development, very few of these books featured families like ours. So, I started creating 'homemade books' starring characters with cochlear implants and integrating speech and language development strategies into the stories, focused on whichever goal we were working on at the time. When my daughter's Auditory Verbal therapist saw these books, she asked if I would publish them so more kids could benefit from them...and so, to cut a long story short, I founded AVID Language and now work with authors from many different countries, all writing books that provide 'mirrors and windows' for deaf children and their typically hearing peers.

For me there's no feeling quite like that when other parents write to me, telling how their child, inspired by one of our stories, said a word for the first time, or pointed to the CIs in one of our books and then to their own 'magic ears'... One thing I have learned through my work and as the parent of a deaf child is that #RepresentationMatters is so much more than a hashtag – it really DOES matter, and it really does make a difference to our children.

Our books are currently available worldwide on Amazon, as well as via many online bookstores. We have titles published in English, Spanish and Danish and (particularly thanks to new collaborations resulting from the CIICA conference) we are hoping to offer additional language versions before too long. While constantly expanding our range of children's books, we will soon also have some more books joining "VOICES of HOPE" in our collection for parents and professionals... Watch this space – you may well know the authors!

You can see the entire AVID Language collection here: www.avidlanguage.com

Tanya Saunders
CI-Mum and founder of AVID Language

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[WORLD NEWS – UK – BATOD – Diversity in Deaf Education Congress](#)

BATOD

British Association of Teachers of
Deaf Children and Young People





The 2024 FEAPDA congress, organised by [BATOD](#) in partnership with the National Council for Special Education ([NCSE](#)) in the Republic of Ireland and the European Federation for deaf associations and organisations ([FEAPDA](#)) took place on 26th and 27th April in Dublin.

The focus of the two-day Congress – Diversity in Deaf Education, encouraged submissions from a wide range of contributors. Delegates had a choice from over 30 different workshops and presentations, in addition to enjoying three excellent keynote speeches and discussing a number of poster presentations. The content of the keynotes, presentations and workshop sessions included updates on research projects, changes in policy and practice, innovative teaching approaches and newly developed resources. Topics presented covered many elements of the education of deaf children and young people, exploring and celebrating the diversity of the population.

The 200 delegates from the UK, Ireland, Europe, North America, Hong Kong and Australia enjoyed BATOD's first international deaf education event.

In addition to the presentations and workshops, the exhibitor space enabled delegates to learn about the latest resources from the many companies and organisations who supported the event.

The access arrangements in place throughout the conference provided many delegates with the opportunity to experience the potential of new technology alongside the highly skilled teams of interpreters. For the first time, at a FEAPDA Congress, attendees saw deaf interpreters working, interpreting from Irish Sign Language to International Sign Language. British Sign Language was also accessed throughout the event. In addition, technology enabled access through sound field systems, connectivity of assistive listening devices and live captions, including translation to other languages on personal devices. The complex logistics of the day in providing access to all presenters and delegates, provided a timely insight into the future of education, meeting the diverse requirements of all.

Delegates shared one of the significant positive experiences gained during this joint FEAPDA, NCSE, BATOD event being the opportunity to network with professional peers from a range of sectors and countries.

BATOD has started the preparations for our 2025 National Conference and will taking on board the feedback and evaluation comments from the joint Congress. Further details will be announced soon on the [BATOD website](#) alongside the various local regional/nation-specific BATOD events.

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WORLD NEWS – UK – BATOD – BATOD Audiology Refreshers

BATOD

British Association of Teachers of
Deaf Children and Young People

The Audiology Refresher free-to-access resource has recently updated two subsections:

- 6.1 Hearing aids <https://www.batod.org.uk/resource/6-1-hearing-aids-has/>
- 6.4 Assistive Listening Technology (ALT) – radio aids and proprietary remote microphone systems <https://www.batod.org.uk/resource/6-4-assistive-listening-technology-alt-radio-aids-and-proprietary-remote-microphone-systems/>

For more information on this resource or if you would like to make a suggestion or contribution, please send an email to: BATODAudiologyRefreshers@batod.org.uk

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WORLD NEWS – USA – ACI Alliance CI Community Engagement Opportunities

Literacy is Supported by Rich Language of the Home and Heart



Listening → Language → Literacy → Reading
Writing

- All children—especially those who are deaf or hard of hearing—benefit from language exposure rich in quantity and quality (Language Nutrition).
- Families are most successful in building their child's literacy when they are comfortable when talking with their child.
- Research shows the benefit of home language on a child's learning and social/emotional well-being.
- Listening allows children to hear the sounds of language, facilitating reading and writing.

References:
Zasche LH et al. J Pediatric Health, 2017. (main audience: pediatric nurses)
Suskind D. Thirty Million Words: Building a Child's Brain, 2015.
Hart & Risley. Meaningful differences in the everyday experiences of young American children. Brookes Publishing, 1995.
Arora S. Language Environments and Spoken Language Development of Children with Hearing Loss. J Deaf Studies 2020.
Too Small to Fail; US Department of Education; UNESCO



Visit the ACI Alliance website to download and share resources for parents of children with hearing loss, adults with hearing loss, and hearing health professionals. Resources include CI candidacy guidelines, tips for CI users, and more. <https://www.acialliance.org/page/resourcestoshare>

Here are a few in more detail:

Listening @ ACI Alliance

Listening @ ACI Alliance is a free monthly email with information on cochlear implants for adult CI recipients (and those exploring CI), parents and family members interested in CI, hearing healthcare providers, educators who work with deaf and hard of hearing children, and anyone wanting to learn more about cochlear implants.

www.acialliance.org/page/ListeningACIAlliance

Join ACI Alliance

Consumer membership is \$10 annually and designed for the public at large and people of all ages with hearing loss and their families.

www.acialliance.org/page/MemberTypes

Cochlear Implant Consumer Advocacy Network (CI CAN)

CI CAN is designed to amplify ACI Alliance efforts with grassroots advocacy. Anyone who has or needs a cochlear implant or supports others may join our network. ACI Alliance staff and volunteers provide training and guidance and there is no cost to join or participate.

www.acialliance.org/page/CI_CAN

Webinars

Webinars are a free series for adults, parents and other family members seeking information on cochlear implants and related topics. Previous talks covered late onset hearing loss, pediatric and adult mapping and sessions, adult rehabilitation, cochlear implant surgery and more, and all are available to watch for free on our website.

<https://www.acialliance.org/page/Webinars>

Consumer and Parent Workshop

The Consumer and Parent Workshop is designed for parents, adult consumers and family members interested in learning more about cochlear implants. It features internationally recognized cochlear implant scientists and clinicians who share up-to-date research and clinical experience in an accessible manner. The workshop can be accessed for free on our website.

www.acialliance.org/surveys/?id=Consumer_Workshop

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ADVANCED BIONICS – How Innovations in Cochlear Implant Technology Come to Life



Have you ever wondered how new cochlear implant features and functionalities are created? Do scientists and engineers sit together in a room every Monday morning and brainstorm potential improvements to work on that week? How does the idea turn into a tangible product or feature? And how do we ensure that this new idea works and is safe?

Unlike typical hearing aids, cochlear implants are complex medical devices that work differently, employing an external device and a surgically placed implant. Developing and obtaining regulatory approval for an innovative cochlear implant is not a fast process and can take many years. This measured and carefully monitored process also ensures that only the best and safest devices are available for our patients.

Tojo Meier, Advanced Bionics Product Manager of Surgical Portfolio walks us through the different steps of developing new CI technology, from ideation to making it available on the market. You can read the full story on our blog, [CONNECTIONS](#).

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[ADVANCED BIONICS – Auditory Skills Training for adults. What it is and how it can help](#)



Hearing technology, such as hearing aids and cochlear implants, help us hear our best, but hearing technology alone is not enough. There is a misconception that wearing hearing aids or cochlear implants is just like wearing glasses. Put them on and you hear clearly!

This is just not the case. It is important to train the brain to hear better. Most of us would never consider running a marathon without any training to go the distance. It is the same with training the brain to hear. When people first get hearing technology, auditory skills training is needed to help make sense of new sounds.

On our blog [CONNECTIONS](#), Valeri Le Beau, Senior Rehab Manager at Advanced Bionics, explains to us the importance of structured, repetitive listening exercises.

Make sure to visit the blog regularly to find stories written by CI experts, CI recipients, or parents of children with CIs. You can read about their hearing journeys and other helpful articles on hearing loss and cochlear implant technology.

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[COCHLEAR - Bimodal control in the Cochlear™ Nucleus® Smart App](#)



"If I had one app to control both, I'd be able to get more control out of how I use my hearing and adjust all the settings a lot more and make the most out of my processor," says 29-year-old Bec, who uses a Cochlear™ Nucleus® 8 Sound Processor on one ear and a ReSound hearing aid on the other.

Bimodal recipients like Bec can now benefit from a new update to the Nucleus Smart App. The update adds bimodal control for recipients with a compatible* ReSound hearing aid and a Nucleus 8, Nucleus 7 or Kanso 2 Sound Processor. It means you can use the Nucleus Smart App to quickly adjust both your hearing aid and sound processor settings to help you achieve your best possible hearing.

Whether it's changing programs or adjusting volume, you can fine-tune both devices at the same time.

Bec, 29 has found using a hearing aid on one ear and a Cochlear device on the other has helped her "get the best of both worlds".

"I chose a ReSound hearing aid because it meant that I could stream to both my ears from my phone, which means that I can take phone calls, I can listen to music and podcasts and hear it in both ears with really good clarity," she says.

Ready to get started?

[Click here](#) or scan the above QR-code to watch how to use the Cochlear Nucleus Smart App.

*For compatibility information and devices visit www.cochlear.com/compatibility and www.resound.com/compatibility

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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 directions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information.

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

ACE, Advance OffStylet, AOS, Ardium, AutoNRT, Autosensitivity, Baha, Baha SoftWear, BCDrive, Beam, Bring Back the Beat, Button, Carina, Cochlear, 科利耳, コクレア, 코클리어, Cochlear SoftWear, Contour, 콘트루아, Contour Advance, Custom Sound, DermaLock, Freedom, Hear now. And always, Hugfit, Human Design, Hybrid, Invisible Hearing, Kanso, LowPro, MET, MP3000, myCochlear, mySmartSound, NRT, Nucleus, Osia, Outcome Focused Fitting, Off-Stylet, Piezo Power, Profile, Slimline, SmartSound, Softip, SoundArc, SoundBand, True Wireless, the elliptical logo, Vistafix, Whisper, WindShield and Xidium are either

trademarks or registered trademarks of the Cochlear group of companies.

ReSound is a trademark of GN Hearing A/S.

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[COCHLEAR - My decision to upgrade and here's what happened.](#)



Have you thought about upgrading your sound processor but wonder what the experience might be like?

Who better to answer these questions than someone who has recently upgraded to two Cochlear™ Nucleus® 8 Sound Processors. We asked Susan, a retired grandmother who upgraded recently from Nucleus 7 Sound Processors.

Q. What was it like getting used to the new technology?

A. It was easy for me. I could understand speech immediately. For a few weeks or months, I noticed that my ears heard differently. Now, I think I hear from both ears with nearly the same pitch.

Since my left ear has been implanted for less than a year, and my right ear switched from the Nucleus 7 to Nucleus 8, I am thinking that my brain simply needed time to consolidate things.

Q. What's been the biggest change?

A. My hearing is clearer than ever. Sounds all around! The transition didn't require any special aural training. I just put them on and went.

The biggest change is that, in most cases, I can understand in restaurants, even if there is low background music.

Just this week, my cousin whom I see frequently, commented while we were in a restaurant that she can tell that I hear better, because she doesn't need to repeat as often.

Q. What features do you like best about your new sound processor

A. Compared to the Nucleus 7, I like the clarity of sound. Music is better and the variety of music that I can enjoy is wider.

Recently, we had the opportunity to attend a small concert of the Vienna Boys Choir. This group of 24 boys had such sweet voices and I could make out the individual singers who had special parts in the performance.

I was moved to tears and this truly was a highlight of our vacation last summer!

Q. Do you stream to your sound processors?

A. When I make or receive a phone call on my iPhone, my phone automatically streams. Nothing special is required to start streaming, once the phone and the sound processors are connected.

Likewise, when I listen to a podcast, audiobook, or any web-based audio content, my phone automatically starts streaming. I also stream FaceTime, YouTube, Facebook, and other websites.

Q. What accessories do you use?

A. With the Mini Mic 2+, I stream movies from my Kindle Fire, listen to my husband and others in the car, and listen to doctors. I also use it to hear tour guides and recorded audio tours, when I can plug their device into the MiniMic 2+.

I love the TV streamer and can easily hear the TV now, but I prefer to also use closed captions.

Q. Do you use devices to control your sound processors?

A. I usually use my phone and the Nucleus Smart App to control my processors. I like that I can control some features of the Nucleus 8 and accessories with my Apple watch. That's very convenient.

Q. What would you say to others who might be hesitant to upgrade?

A. I would say, go for it. The processors get better and better, and I certainly want to maximise my hearing possibilities. There is a learning curve, and patience and dedication is required. I would encourage others to be open to new technologies and to involve others around you for help.

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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.

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

Cochlear's range of Smart Apps and Support Apps are available on App Store and/or Google Play. For information regarding the sound processors, operating systems and devices that are compatible with the Cochlear's range of Smart Apps and Support Apps, visit www.cochlear.com/compatibility.

ACE, Advance Off-Stylet, AOS, Ardium, AutoNRT, Autosensitivity, Baha, Baha SoftWear, BCDrive, Beam, Bring Back the Beat, Button, Carina, Cochlear, 科利耳, コクレア, 코클리어, Cochlear SoftWear, Contour, 콘트واء, Contour Advance, Custom Sound, DermaLock, Freedom, Hear now. And always, Hugfit, Human Design, Hybrid, Invisible Hearing, Kanso, LowPro, MET, MP3000, myCochlear, mySmartSound, NRT, Nucleus Osia, Outcome Focused Fitting, Off-Stylet, Piezo Power, Profile, Slimline, SmartSound, Softip, SoundArc, SoundBand, True Wireless, the elliptical logo, Vistafix, Whisper, WindShield and Xidium are either trademarks or registered trademarks of the Cochlear group of companies.

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MED-EL – HearCare App: Convenient Care. Anytime. Anywhere.



With MED-EL's new HearCare app for smartphones and tablets, CI users can now test and optimise their implant and audio processor status themselves, anytime, anywhere. HearCare allows remote access and personalised care without the need for hospital visits. This liberates RONDO 3, SONNET 2, and SONNET 2 EAS users from additional in-person appointments, which can be time-consuming and costly.

Here's what you can expect with HearCare:

- Professionals can change fitting parameters remotely.
- A Guardian Function enables parents to check their child's processor status in real time, and an alert function gives them added security.
- A system check provides information on battery status as well as on other functions that might compromise hearing performance, such as dirty microphone covers. This feature is particularly helpful for the youngest users who cannot give feedback about their hearing quality.
- Summertime is travel time. With the new HearCare MED-EL app, users can download their current fitting parameters from the cloud into a spare processor, if needed, so they can enjoy a relaxing holiday.

The HearCare app offers many more benefits that make CI users' lives easier. But what about data security? MED-EL uses ISO 27001-certified software to safeguard against data and cyber fraud, giving users additional peace of mind.

For more information on the new HearCare app and to download it, visit: [HearCare MED-EL \(medel.com\)](https://medel.com)

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