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[Message from the President](#)



Photo – Arriving at the EURO-CIU summer camp, after a very long journey and a great deal of planning.

I hope that you have enjoyed nice summer holidays. The summer months have been relatively quiet as far as CI conferences are concerned, but momentum is clearly building up again now as we head into autumn.

The EURO-CIU Summer Camp in Telč, Czech Republic, was a resounding success! You can read more about it below.

SAVE THE DATE! EURO-CIU's next Symposium 30 years of **EURO-CIU: Past, Present and Future** will be held in Istanbul, Turkey, on **4th-5th April 2025**. Our 30th anniversary is a good time to reflect on what has been achieved over the last decades, as well as to recognise the challenges that we will face in the future.

We must elect a Vice-President and Secretary to our board in Istanbul. If you would be interested in one of these roles, please make your interest known to your EURO-CIU member association. Of course, you can also contact existing board members for more information.

Robert Mandara
President, EURO-CIU

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[Message from the Editor of the EURO-CIU Newsletter](#)



Well, 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 2 December 2024. Just e-mail them to me at newsletter@eurociu.eu

With every good wish.

Brian Archbold (Editor)

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[EURO-CIU Summer Camp in Telč – Report from a participant](#)





When you have grown up amongst people who don't have a cochlear implant or hearing device, you almost think that you have normal hearing, but sometimes you have needs that normal hearing people do not understand. You don't think that there is the possibility that someone else could have your same feature, because you have never seen him or her before.

This summer, in Telč, I discovered a new world, so many things about cochlear implant users that I am still thrilled even only remembering them.

I met the rest of the Italian group (four teenagers and the leader) at the airport, just before the flight, and I was surprised and pleased to meet those who now are my friends. I immediately felt like we all could understand each other much better than our parents, because we wore the cochlear implant, so we knew how it feels to have one.

Once we arrived in Telč, in this beautiful university campus in the centre of the city, the first evening we did presentations of our countries, in which we explained something about it. With a special finale: after each presentation the guys of each group distributed a typical sweet or food, so that we experienced a gastronomic food exchange (when we shared the Sardinian typical guttiau bread, all people wanted more and more, especially the English ones).

During EURO-CIU summer camp, we did a lot of countryside walks and activities, and this made us get closer and closer, chatting with each other. Thanks to morning and afternoon activities organised during the day, I got to know the different groups – Bosnian, English, Romanian, Swedish, Luxembourgish and Czech. I found friends almost immediately. Sometimes I stayed with my group, but at a certain point I started to spend almost all the day with some foreign mates. I enjoyed the spirit of friendship among all participants that seemed to be linked by a special complicity.

The group was like a family, something that never happened to me.

Thanks to this experience I made new friends and I also increased my level of English. I would like to thank Marina, her gorgeous Czech organisation Suki and Robert, the president of EURO-CIU, who made all this possible. I really hope to take part in the next EURO-CIU summer camp. Thank you so much for what you've done for our cochlear implant community!

Vittoria Bianchi – AGUAV – Italy

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EURO-CIU Summer Camp in Telč – Report from the President of EURO-CIU



The EURO-CIU Summer Camp was held 20th – 27th July, in the stunningly beautiful UNESCO World Heritage Site of Telč, Czech Republic. We were blessed with good weather. The event was mainly organised by SUKI, the Czech EURO-CIU member association. The Czech volunteers and participants did a fantastic job of making everyone feel welcome.

The camp was full to capacity, with participants from nine countries. The whole week was very inclusive and all got along very well. The degree of caring for each other was very well illustrated when everyone willingly stopped a game of football, on AstroTurf, to search for a participant's ear hook – akin to looking for a needle in a haystack – and even found it!

The day before the camp, there was a global Microsoft problem threatening everyone's flight schedules. Fortunately, most delays were minimal, although one small group's journey got delayed by a day.

For participants, the priority was to have fun and to make international friends with CI-using peers. In one case, a participant had received implants as a baby but, until coming to the camp, had never met another CI user. The camp certainly changed that! There's great comfort for all of us in knowing that we are not alone and that we share many of the same challenges.

Fun activities included hiking, swimming in crystal clear waters, making music, dancing, partying, visiting the adjacent castle, cooking sausages over a fire, enjoying foods from different countries, a "pub" quiz and so much more. There was a lot of laughter.

Sessions were held to get the youngsters thinking about CI advocacy, by considering and comparing the challenges that they face in their respective countries. Even today, there are huge differences in eligibility for CI, access to CI and funding.

The youngsters were also given the amazing and very important opportunity to better understand the hardware inside their heads, and the skills of the surgeons who installed that hardware. There was much amazement at how tiny the electrodes are, and how difficult they are to insert into surgeons' training aids.

I grew up in an era before CI and remember how difficult life was for myself and my peers who were trying to struggle along with inadequate hearing aids. Ultimately, my generation suffered with self-confidence, getting proper education and meaningful employment. It absolutely warms my heart and fills me with joy to see how CI technology has changed the lives of young people, perhaps far more than they will ever be able to fully appreciate.

Their self-confidence, intelligence, articulation, and pride in being CI-users just blows my mind. It feels good to know that every single one of them will be able to go on to achieve even more great things. The youngsters arrived at the camp confident, but I felt that confidence rise even higher over the course of the week. That is why it is important that we find ways to keep on hosting the camps.

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[EURO-CIU NEWS – Survey on Electronic Instructions For Use \(eIFUs\) for medical devices](#)



In February we asked our members for their opinions on digital instructions for use (eIFU's) in medical devices.

Now the EU has launched a survey to learn more. Although the survey is aimed at professional users, question 12 is especially relevant to CI users.

The questionnaire takes only 5 minutes to complete and can be found at this link: https://ec.europa.eu/eusurvey/runner/Survey_eIFUs_medicaldevices_2024

Best wishes,

Robert Mandara
President EURO-CIU

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[EURO-CIU NEWS – European Disability Forum meetings – Conference, AGM in Ljubljana](#)



The president of European Union of the Deaf, Sofia Isari, with Sari Hirvonen-Skarbö (top); and the delegates at the AGM (below)

The Belgian Presidency of the Council of the EU kindly supported the European Disability Forum (EDF) meeting. One of the topics was EDF's campaign for the European Union elections 2024. It was the Manifesto on the European Elections: "Building an inclusive future for persons with disabilities in the EU". It is to realize a Union of Equality for persons with disabilities with the Convention on the Rights of Persons with Disabilities (CRPD) as its compass. It was to involve people with disabilities in the development of political programmes for European elections and to increase the number of candidates with disabilities. It was to activate the EU candidates to sign the manifesto. I had good discussions with some candidates at the election campaign in Helsinki and I got their signatures. The list of signed names from EU countries are seen on the website of EDF.

How technology could help to decrease unemployment of the persons of disabilities

The General Assembly in Slovenia was preceded by the conference "Technology in employment. A step towards inclusion". There was panel discussion about the findings of the DATA Project, European research on Digital Skills. The inadequate employment rate for persons with disabilities was stressed. Research was carried out in 27 countries. Governments, companies and others need to prioritize an inclusive, open labour market.

It became clear that 40% of employers lack experience with candidates with disabilities. Employers and tech companies must involve organizations of persons with disabilities in the development, design and deployment of assistive tools. It was focused that persons with disabilities would learn more on digital skills and Artificial Intelligence. Now EDF is working on disability-inclusive AI and the potential of AI in simplifying and enabling access to information.

Members from the EDF Youth committee underlined that there are barriers in the recruitment process and in accessing accommodations in the workplace, especially when

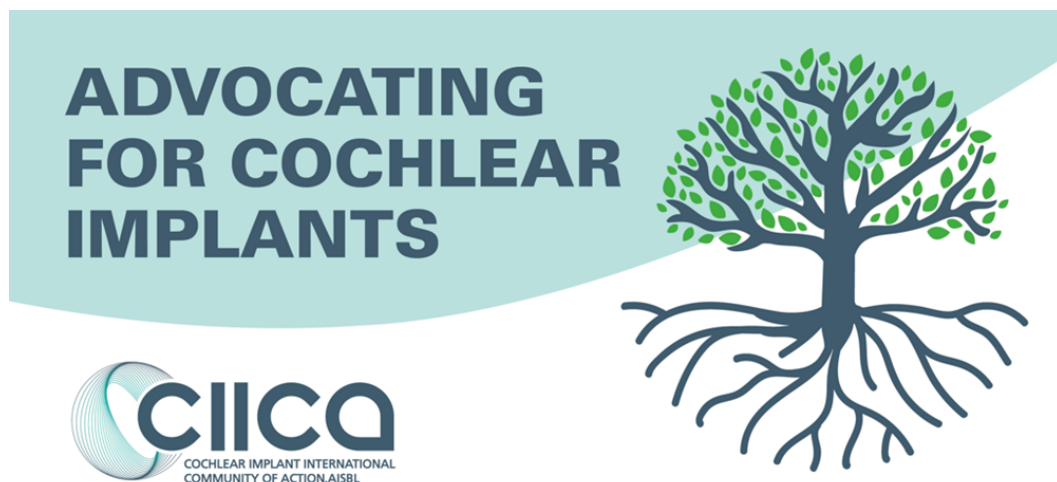
workers are young and it's their first experience. They underlined that training is key, that it must be accessible and include training on digital tools.

At the AGM, the strategy for the next four years was discussed. The process presented the following emerging objectives: membership engagement and capacity building; diversity and inclusion; communication and dissemination and the strategic alliances. The European Disability Rights Strategy is being progressed. The political agreement on the European Disability Card and European Parking Card was celebrated. The EDF Youth committee is active, they have held 8 workshops, attended 32 events and written several blogs.

Sari Hirvonen-Skarbö
EURO-CIU's EDF Delegate

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CIICA Launches New Practical Guide for Cochlear Implant Advocacy



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. To help address this and support the continued effort in individual regions and countries as well as globally, CIICA has produced this practical guide to advocacy on CIs.

The 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.

The guide was launched at CIICA's first Advocacy conference where delegates warmly welcomed it and has had a large number of downloads since then, suggesting that advocacy groups are finding it a useful resource. CIICA followed this up with an online event: go to [CIICA LIVE: CI ADVOCACY IN ACTION – CIICA \(ciicanet.org\)](#) for the captioned presentations. The guide will be developed over the coming months, and we will be posting several videos covering some of the main topics and case studies used in the guide. This will be followed by further additions to the guide and further training events, so do look out for these on the CIICA website. Our updates will keep you informed!

If you want inspiration, advice and knowledge for planning your future campaigning, the

guide provides evidence and resources specific to campaigning on CI provision. [CIICA ADVOCACY GUIDE](#)

This is a developing resource – with more to come! Download the guide here <https://ciicanet.org/wp-content/uploads/2024/05/CIICA-ADVOCACY-GUIDE.pdf>

Brian Lamb OBE

EURO-CIU is a founding member of CIICA.

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AUSTRIA – CIA (Cochlea-Implantat Austria) – 20 years of CIA-Lower Austria



The strength of self-help groups also lies in their proximity to those affected – both factually and locally. CIA (Cochlea-Implantat Austria), which was originally founded in Vienna, is pleased to also have many local CIA groups, of which the Lower Austrian one has the longest-standing tradition.

On 10 August 2024, members, relatives, founders, a delegation of CIA Austria and several special guests gathered at a restaurant garden in Lower Austria to celebrate 20 years of the CIA group in Lower Austria. 20 years ago, the ENT surgeon and then head of the ENT department in St. Pölten and the CI team, Prof. Klaus Böheim, asked his patient Trude Moser, if she wanted to lead a new CI self-help group for at least six months. Rather reluctantly, she agreed at the time – 20 years later she is still very active as a chairwoman of the CIA Lower Austria!

Prof. Böheim, now retired, was our guest of honour at the anniversary event, as were Ronald Söllner from the umbrella association of self-help groups in Lower Austria and Max Schlögel, who has been looking after CI patients at the University Hospital of Lower Austria since the start of the CI programme there. The event was complemented by a slide show about 20 years of CIA-Lower Austria. Deputy chairman Heinz Kirchschrager, who also played at the EURO-CIU Symposium in Vienna, entertained the group with traditional dance music.

Photo ©Heinz Kirchschrager

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AUSTRIA – CIA (Cochlea-Implantat Austria) – 20th CIA-Summer Days – an Austrian Success Story



In 1999, families with children with cochlear implants met for the first time in Velden on Lake Wörthersee for four days of holidays. The event had to be cancelled in 2020 due to the corona, but in July 2024 we officially celebrated the 20th Summer Days. The programme combined the tried and tested with the new: CI info breakfast, rehab tips, parents' workshop and CIA evening, arts and crafts for the little ones, a family excursion, dinner at the nearby Castle Mageregg and a cocktail evening at the hostel, a joint trip on the steamboat MS Thalia to mark the 20th anniversary and the popular Family Olympics.

As always, the kids' theatre performance marked the highlight. Led by true professionals in their field, children and young people with and without CI demonstrated their talents at the performance called 'Play like a Champion' in acting, music and dance. The children found self-affirmation, the parents were proud, and the CI specialists present were also deeply impressed. Hearing loss as an obstacle to a creative career? Not with a CI!

In addition to the varied programme, there was also plenty of time for families to share valuable experiences about the different life situations with CI, from kindergarten and school to university and starting a career. That's why the Summer Days were extended to five days for the first time this year.

Photo ©Carmen Kronawettleitner

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FINLAND – Kuuloliitto CI – The Finnish Federation of the Hard of Hearing (FFHOH) – The Nordic Summer Days in Kuopio



Group photo of the participants (top), and at the top of Koli Hill, with Interpreters on the right.

At the end of July, more than fifty people participated in the Nordic Summer Deaf Days in Kuopio, Spa Hotel Rauhanlahti. The participants were cochlear implant users and some with hearing loss, and some had a relative with them. Most of participants were Finns, surprisingly only a few came from Denmark and Sweden. The event was open to everyone, and participants came from other countries; Estonia, Ireland, United Kingdom, Germany and Switzerland.

Summer days, previously called The Nordic Summer Week, have been organized since 1981, every third year in some Nordic country. The last event before Finland was in Haapsalu, Estonia. The future of the 25th summer days is under consideration, as the background organization VDNR (Late Deafened Nordic Committee) will be closed this autumn. The working team, which consisted of members **Kuuloliitto** CITO and KUTO

working groups have planned this event for over two years.

Participation and communication were as accessible as possible.

The aim was to make participation in the four-day event accessible to everyone. Written interpretation was in Finnish and English. A signed Finnish and an induction loop were also used. If English was a problem, there was translation to Finnish language.

Some participants had a personal interpreter with them, so they could discuss from morning until late at night. The interpreters were working especially in the evenings when participants sat together in a karaoke bar. This way, everyone was able to follow the conversation despite the noise.

It was possible to download the interpretation link to their mobiles, where they could read the guide's explanation in the bus, for example. The interpreters were also with us at the top of Koli Hill, where we all climbed with our guides to admire the magnificent scenery of lakes and hills.

Versatile programme to acquaint the local culture.

There was a lunch cruise in Lake Kallavesi, a sightseeing tour to Kuopio city centre and a visit to Puijo Tower. If they wished, they could attend a lecture by Antti Hyvärinen, ear, nose and throat specialist; he talked about CI surgeries in Finland. In Kuopio University Hospital, Cochlear Implant surgeries are performed under local anaesthesia, depending on the patient's condition.

In addition to lectures, participants were able to participate in craft workshops and play Finnish outdoor games, such as mölkky and darts. Bathing in a smoke sauna was a new experience to many Finns as well. After the timber drafting show there was local Savonian fish pasty and Karelian pies to eat.

Being together is great peer support and to exchange information.

Each country presented their organization and activities. An interesting story was told by Mary Gallagher, Ireland. As a child, she was pushed by a car, apparently because of hearing loss. She underwent a hearing test, which yielded good results. Many years later, she met an ear doctor who suggested a cochlear implant. Her husband has noted that Mary's quality of life improved considerably after receiving CIs. She enjoys life now and is active at the organization CHIME in Dublin.

One of the reasons for joining summer days was to meet old acquaintances. They have met each other at the summer camps of IFHOHYP, which were for young people with hearing loss. They have been in touch ever since and have organized some summer meetings on their own. Now it was considered whether it could be arranged in a more organized way and better informed, so more adult CI users and persons with hearing loss could join in. Let's hope that a solution can be found for which associations would be able to organize this adult summer event.

Sari Hirvonen-Skarbö

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[GERMANY – DCIG – Bavarian Cochlear Implant Association – Concert of the MuCIs Choir of the Hearing Impaired at the Bavaria State Horticultural Show, held in Kirchheim near Munich](#)



Even CI and hearing aid wearers can sing!

"My son/daughter thinks my voice is terrible."

"At school, my music teacher said I couldn't sing."

Statements like these unsettle many hearing-impaired people, and often even those with good hearing. People with CI or hearing aids quickly become doubtful about their own (singing) voice because the devices amplify or attenuate certain frequencies disproportionately depending on the individual setting. The particularly high and low tones are even "cut off" completely because they are not important for understanding speech. But to understand music, you need a complete and comprehensive sound image. A music program can help with this, but this is usually only included with hearing aids that require additional payment. Of course, this program cannot replace the ability to understand music naturally.

Singing and making music means one thing above all: joy in life. No one – whether they have good or bad hearing – should be put off by thoughtless comments from relatives or friends! Singing in a choir is ideal because it is not noticeable in the overall sound if one or two notes are off.

The fantastic choir of the hearing impaired proved this on Sunday, August 18, 2024 with a successful performance at the Bavaria State Horticultural Show, held in Kirchheim near Munich. Under the direction of the wonderful Barbara Roberts, the courageous singers showed that you can have fun singing together even with hearing loss. The audience was treated to a colourful potpourri of well-known songs such as "La Cucaracha", "Capri-Fischer" and "Wochenend' und Sonnenschein" from the choir's diverse repertoire. A special highlight was the song "Heute gut, morgen schlecht", which was rewritten especially for the choir of the hearing impaired (original: "Heute hier, morgen dort" by Hannes Wader). The song is about the challenges of life with hearing impairment. In collaboration with a deaf person, the signs that match the text were developed and practiced and performed by the singers.

Whether Bavarian, German or English: the singing was done with genuine joy and infectious enthusiasm. The audience did not let the bad weather dampen their spirits and by the time of the encore ("This little light of mine") everyone was joining in, because: ANYONE can sing! The approximately 50 spectators were particularly impressed by the great fun that was expressed while singing and by the variety of the colourful programme

that was presented.

A particularly big compliment goes to our long-time choir director Barbara Roberts, who always manages to encourage us to sing despite our hearing loss. With a lot of effort, patience and incredible empathy, she helps us to develop and expand our own singing voices without neglecting the fun! Doubts and uncertainties are quickly forgotten.

Last but not least, we would like to thank Regine Zille, who has been ensuring the choir's continued existence and smooth organization for over eight years with her tireless commitment.

The choir for people with hearing difficulties lives from its great members! New singers are very welcome. We meet every 4th Monday of the month in the BLWG premises at Haydnstrasse 12 in Munich (near Goetheplatz, not far from the main train station). Current dates can be found on the [BayCIV website \(MuCIs events\)](#). We look forward to seeing you!

Please find the video with this link: <https://youtu.be/iBpjYvzoxFM>

Marion Kappelhoff

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SPAIN – AICE – Summer Camp 2024



The 10th edition of CampAICE of Federación AICE's summer camp has been celebrated and, as it could not have been otherwise, it is again breaking records. For the second consecutive year, the maximum capacity has been reached, with the participation of 44 campers, coming from eleven different Autonomous Communities. And all this in less than a month after the opening of registration.

The camp is fully accessible thanks to the implementation of magnetic loops, live transcription and amplified sound. In addition, it is staffed by instructors who are also cochlear implant users and former participants, which fosters an exceptional connection and positive reflection among the young attendees.

The main purpose of this summer camp was to be a place where we can learn more about how young people with cochlear implants live in different parts of Spain and above all to empower the participants. For this, we organized workshops, talks and activities to teach them things that will help them in their day-to-day life. With these activities we want them to feel more self-confident and to better understand how their cochlear implant works and what they need to do to take good care of it.

It is difficult to reflect everything we have experienced during the camp, but we can summarize it in that the friendships of CampAICE have marked us and...

... **“We can’t hear, but we know how to listen”**

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RELATED CONGRESS – HEARING Round Table and Keynote Lecture – 17 September 2024



hearing round table

Best Practices in Hearing Implantation for Emerging Nations

**Sept 17, 2024
14:00 CEST
online**

					
Genetics in Emerging Nations by Prof. Dr. Usami, Japan	Prof. Dr. Baumgartner Austria	Prof. Dr. Gavilán Spain	Prof. Dr. Castilho Brazil	Prof. Dr. Müller Germany	Prof. Dr. Zernotti Argentina

[Keynote Lecture](#)

[The Round Table](#)

It is with great pleasure that we invite you to join us for our forthcoming Round Table and Keynote Lecture. This exclusive event will take place online at 14:00 CEST on the 17 September, 2024.

Themed “Best Practices in Hearing Implantation for Emerging Nations,” this event underscores our dedication to supporting the World Health Organization’s hearing initiatives, with a strong emphasis on elevating standards in emerging nations. Bringing together distinguished experts such as Prof. Dr. Gavilán, Prof. Dr. Castilho, Prof. Dr. Müller, and Prof. Dr. Zernotti, alongside a keynote lecture by Prof. Dr. Usami on “Genetics in Emerging Nations,” this event promises enriching discussions and insights.

Aligned with our mission to enhance quality standards and clinical practices, particularly in

emerging nations, HEARRING Group endeavours to provide valuable insights and practical information for patient care in these regions. This event not only aims to engage those present in person but also to connect with audiologists and surgeons worldwide online.

This event will receive an internationally valid accreditation, which you may claim few weeks post event – simply by registering on the HEARRING Boost (the educational portal of the HEARRING Group). The certificate download will be available under a section corresponding to the HEARRING Autumn Round Table 2024.

[Register at HEARRING Boost](#)

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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](#)



The 36th World Congress of Audiology is coming up very soon, 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 round tables 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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[WORLD NEWS – The World Hearing Forum](#)



The World Hearing Forum (WHF), 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 are open from August 15 to October 15, 2024. [Apply here.](#)

You may be interested to learn about Joanna's journey:

Joanna Białasz, Poland

Joanna Białasz, a 17-year-old Polish journalism student, exemplifies resilience and determination. Diagnosed with profound bilateral deafness before her second birthday, Joanna received a cochlear implant in her left ear, opening up a world of sounds.

Joanna learned to communicate verbally through dedicated rehabilitation and support from her parents, who founded an association for children with hearing impairments in Poland. Her education at a private primary school included tailored classes to improve reading, writing, and sign language skills.

Embracing a multifaceted approach to personal growth, Joanna engaged in contemporary dance, piano lessons, and foreign language studies, particularly excelling in English and French. These diverse experiences have shaped her into a typical teenager who relishes life, with passions ranging from theatre and music to drawing and swimming.

Joanna's journey extends beyond her hearing impairment; she explores the Japanese language and culture and dreams of visiting Japan. Importantly, Joanna advocates for respectful language, preferring terms like "person with a disability" or "cochlear implant user" over "disabled".

Her story is a testament to the power of perseverance, family support, and personal determination. Joanna's inspiring advice encapsulates her spirit: "If you have barriers, don't cry, just dream. And make your dreams come true".

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WORLD NEWS – UK – Auditory Verbal UK (AVUK) – Deaf young people meet Members of the Welsh Parliament calling for urgent investment in Auditory Verbal therapy that supported them to listen and talk



Two cochlear implant users and their families met members of the Welsh Parliament (Senedd) in Cardiff in July to challenge expectations of what deaf children can achieve and call for urgent investment in Auditory Verbal therapy which supported them to have the same opportunities as their hearing peers.

10-year-old Nathaniel and 27-year-old Harrison joined charity Auditory Verbal UK (AVUK) and shared their inspiring stories of what they are doing in their lives and how Auditory Verbal therapy supported them in their early years to learn to listen and talk. They met

Members of the Senedd to discuss the [Hear Us Now campaign](#) and how the Welsh Government can improve outcomes and opportunities for deaf children by investing in early and effective support to develop language and communication.

Harrison, who is a graduate of Aberystwyth University and now works for the Royal Mint and lives in Cardiff, said: *"It is thanks to the determination of my parents to get early and effective support for me with my cochlear implants and Auditory Verbal therapy that I don't feel being deaf has held me back in any way. I love music, can play guitar, and saxophone and have a huge passion for sport especially surfing."*

Despite 84% of adults in Wales believing Auditory Verbal therapy should be available through the National Health Service (NHS), less than 10% of deaf children can currently access this support and there are no qualified Auditory Verbal Therapists in Wales.

Nathaniel, who loves school, football and shopping, was joined at the Senedd by Mum Siobhan. She said: *"Deafness is a disability but with the right support deaf babies and children like Nathaniel can achieve their potential. Thanks to the amazing cochlear implant technology and the specialist Auditory Verbal therapy programme he is reaching his academic targets as he should. AVUK played an important part in helping make our dreams for Nathaniel speech and listening come true. But things need to change for other Welsh families which is why we were pleased to be at the Senedd and raise awareness as well as ambition and investment so all deaf children can achieve their potential."*

To find out more about supporting investment in life transforming Auditory Verbal therapy [visit our campaign page here](#).

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[WORLD NEWS – UK – Auditory Verbal UK \(AVUK\) – Entries open for second year of Claire Campbell Award recognising outstanding achievements of deaf children and adults supporting them](#)



The outstanding achievements of deaf children and young people, and the adults who have gone above and beyond to support them, are to be recognised for the second year with a now-annual award in memory of Claire Campbell, a mother of two deaf children who wear cochlear implants and a committed volunteer and ambassador of charity Auditory Verbal UK up until her death in November 2022. **Entries are open now** and close on 20th September 2024.

Claire and her husband, Chris attended Auditory Verbal UK's family programme of Auditory Verbal therapy with two of their children to support the development of their listening and spoken language and shared their experiences worldwide through a popular blog, Alice's Ears. The family became committed to helping more deaf children and their families have vital early support.

At the launch of the 2024 awards Chris said: *"The 2023 awards were such a perfect way to honour Claire and as a family we were overwhelmed by all the entries which demonstrated truly outstanding achievements both proving what deaf children and young people can achieve as well as adults who are going above and beyond to support."*

"It is clear that Claire's passion and legacy to ensure all deaf children can achieve their potential lives on in so many wonderful individuals and teams. All of the entries were

inspirational in the work they do, proving over and over again that being deaf does not have to be a barrier to any aspiration. I can't wait to see even more amazing entries for 2024 and I know that choosing the winners is going to be as tough a job as it was last year."

There are two categories for the awards:

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

Entries can be made in several ways, including:

- Thank you letter or letter of appreciation
- Story
- Poem
- Newspaper article – with a headline, story and photo as if it appears in a daily newspaper.
- Cartoon
- Drawing

And should be emailed to jane.warriner@avuk.org by midday on September 20th, 2024

The 2023 winners were:

- Lauren Press (18) was diagnosed as profoundly deaf soon after she was born and wears cochlear implants and was supported to learn to listen and speak with Auditory Verbal therapy. She was nominated for the award by her school for her "drive and motivation and dedication to helping others understand deafness and to help improve outcomes for all deaf children."
- St George's Hospital Auditory Implant Service in Tooting, South London, were nominated by the family of a deaf teenager who said: "We applaud each and every one of them for going above and beyond in positively impacting, changing and continuing to support so many children and young people throughout their hearing journeys. Our son is testament to that, and they have had an enormous impact on him throughout his entire hearing journey."

Entries are welcome from the UK and overseas and close on September 20th. More information is available on the [award page](#).

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[WORLD NEWS – USA – Stepping Up to the Plate: RALLY CAPS Starring Judd Hirsch, Amy Smart, and Kids with Cochlear Implants Who Use Listening and Spoken Language Hits Home September 10th](#)



The heartwarming film RALLY CAPS, starring Academy Award nominee Judd Hirsch, Amy Smart, and Carson Minniear, will be released worldwide on September 10, 2024.

RALLY CAPS, written and directed by Lee Cipolla, is a poignant coming-of-age story adapted from real events, capturing the friendship between two boys, Jordy and Lucas, as they navigate challenges and find strength through baseball. Based on actual events, it was adapted from the book by the father-daughter writing team of Stephen J. Cutler and Jodi Michelle Cutler.

The story centres around a young boy, Jordy, who is seriously injured during a youth baseball tryout. At a summer camp, he bonds with a deaf boy, Lucas, who recently had cochlear implant surgery. Their friendship becomes the driving force as the pitcher/catcher duo leads their team in the camp championship game.

The deaf character, Lucas, is based on Co-Author Jodi Michelle Cutler's son Jordan Del Dottore. She says, "I have dedicated the past 27 years of my life to inclusion, accessibility, and cochlear implant advocacy, and I have waited with patience and persistence for the day that my deaf son with cochlear implants who can hear and speak would be represented in film. That day has finally arrived."

The film was produced by Lee Cipolla, Katherine Borda, William Garcia, Amy Williams, Stephen J. Cutler, Jodi Michelle Cutler, and Curtis Pride.

To watch the trailer, [click here!](#)

RALLY CAPS is being distributed by [BMG-Global](#), a leader in family-friendly content.

The film is sponsored by Sonova/[Phonak](#) companies committed to improving the lives of the hearing loss community.

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[WORLD NEWS – USA – ACI Alliance update](#)



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

CI2025 Boston: Conference on Cochlear Implants – Abstracts Open!

ACI Alliance is hosting its annual clinical research meeting April 30-May 3, 2025 in Boston, Massachusetts at the OMNI Seaport Hotel. Abstract submissions are currently open, and we encourage hearing health professionals and educators of children who are deaf or hard of hearing to submit an abstract and plan to be at CI2025. CI2025 will also continue to build on existing Special Interest Group (SIG) meetings, including a new Educator SIG that first met at CI2024 Vancouver. Registration will open in late 2024 with early bird and membership discounts available. <https://ci2025boston.org/>

Paediatric Cochlear Implant FAQs

Information about hearing loss options and cochlear implants can be overwhelming for families of children with hearing loss after a diagnosis. Our Paediatric FAQ resource page is a helpful start-point resource for families wondering if cochlear implants may be right for their child. <https://www.acialliance.org/page/Clinfantsandchildren>

CI2024 Vancouver International Conference Session Material

As presenters give permission to post their materials, we will be adding them to our website. This will include session power points and videos. [CI2024 Vancouver - American Cochlear Implant Alliance \(acialliance.org\)](#)

Adult Rehab Blog - How does noise level impact speech understanding? What can we do about noise to support communication?

A significant challenge faced by people who use cochlear implants – and anyone with hearing loss – is understanding speech in noisy places. Cochlear implant technology offers options to help CI users cope with the challenges of listening in noise including directional microphones, dedicated maps/programs, streaming options, and assistive listening devices. However, more than these technology advances may be needed in certain listening situations regularly encountered. [How does noise level impact speech understanding? What can we do about noise to support communication? - American Cochlear Implant Alliance \(acialliance.org\)](#)

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ADVANCED BIONICS – Music and Deafness



Martina has been deaf since birth, but it wasn't until the age of four that she was diagnosed with severe bilateral sensorineural hearing loss by the team of audiologists at the Policlinico Federico II in Naples, led by Dr. Auletta. As she grew, Martina discovered her love for music, especially the piano. Marina writes in her blog article, *"because of my hearing loss, the beginning of my musical journey can be described as a continuous pendulum between love and hate."*

Despite being a candidate for cochlear implantation, Martina was afraid that she would not be able to identify and discriminate the finer nuances of music with a CI. With her hearing getting worse and forcing her out of the Conservatory, Martina eventually reconsidered *"My switch-on appointment was a disappointment. Everything sounded electronic. [...] Time, however, is transformative. In just three months, I was able to achieve 100% in speech understanding, even in noise. I could recognize consonants such as F, V, S, C, G, Z— sounds that I could not hear before with hearing aids."*

In November 2019, Martina felt confident enough to enroll again in the San Pietro a Majella Conservatory of Naples, where she graduated in 2021, and where she was admitted with honours to a two-year piano master class with a solo focus. She writes, *"I can finally play the other instruments. I can listen to the orchestra without problems, so much so that I can recognize which instrument comes in later than the ensemble. I can hear the nuances of sound from fortissimo to pianissimo. I recognize notes without problems. I can accompany singers. In short, the AB cochlear implant has enabled me to do everything that I previously thought was impossible."*

You can read Martina's full story on Advanced Bionics' blog, [CONNECTIONS](#). Make sure to visit the blog regularly to find powerful stories from CI experts, CI recipients, or parents of children with CIs about their hearing journey and other helpful articles on hearing loss

and cochlear implant technology.

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ADVANCED BIONICS – Marvel at the possibilities – Expanded linked two-ear solution



Hearing with both ears helps us hear better in noisy situations, know where sounds are coming from, and makes hearing less tiring. **(1), (2), (3)** Together with our sister company Phonak, **AB is the only company to offer linked two-ear solutions** with hearing aids and cochlear implants designed to “talk” to each other and work together as a pair. Now AB’s Marvel is also the only CI system with a CROS device.

For people who have severe to profound hearing loss in both ears but hear with only one Marvel CI, CROS gives them another possibility to hear from all around them. Having a CROS device on the ear without Marvel CI allows it to pick up sounds from that side and send them to the Marvel CI. This way, listeners can have a more complete sense of their surroundings and follow conversations from all directions, especially in noisy situations such as restaurants or in the car.

This means **no matter your hearing loss, Marvel has a flexible linked two-ear solution for you**. This could be with two Marvel CIs, a Marvel CI and a Phonak Link hearing aid, or a Marvel CI with a CROS. Great things are coming with Marvel CI, and we can’t wait to share them all with you. [Click here](#) or contact your local AB representative to learn more!

Note: Advanced Bionics cochlear implants are indicated for severe-to-profound bilateral sensorineural hearing loss or severe-to-profound unilateral hearing loss.

(1) Koch DB, Soli SD, Downing M, and Osberger MJ. 2009. Simultaneous Bilateral Cochlear Implantation: Prospective Study in Adults. Cochlear Implants International (February 26), Cochlear Implants International, n/a. doi: 10.1002/cii.413.

(2) Zeitler D, et al. 2008. Speech Perception Benefits of Sequential Bilateral Cochlear Implantation in Children and Adults: A Retrospective Analysis. Otology & Neurotology. 29 (3): 314-325.

(3) Dunn, C, et al. 2008. Comparison of Speech Recognition and Localization Performance in Bilateral and Unilateral Cochlear Implant Users Matched on Duration of Deafness and Age of Implantation. Ear and Hearing. 29 (3): 352-359.

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Have you turned down a career opportunity because you were worried about your hearing loss being a barrier?

An unconscious bias in the workplace is largely to blame for that says, Sandra Ballij, social entrepreneur and CEO of Ctalents, a recruitment agency that specialises in placing people with vision impairment and hearing loss.

How Sandra built a career that helps others find theirs

While at university almost 20 years ago, Sandra found herself briefly in a wheelchair as the result of an infection in the legs.

“No one talked about my future anymore – everyone was focussed on the disease. I felt erased, unseen. I felt I had no future, no outlook anymore. Nobody should have this feeling. Everyone should be seen, heard and appreciated for their talents.”

Strategies for career seekers

Sandra recognises that applying for a job with hearing loss or returning to the workplace after receiving a cochlear implant can be a challenge.

Sandra offers some tips to consider:

- It might be a good time to consider a new role or area of work. Don't confine yourself to past roles. Play to your strengths and think laterally about your skills.
- If listening fatigue is a barrier, mix up your day and work schedule. Remove your sound processors if you need to tune out background noise and give yourself a break. Find a balance between meetings and focus time.
- If you're looking for an office job, research tools that can help you, such as live subtitling or transcription options for video calls.
- Don't be afraid to connect with other people. Most people struggle with something – be open about it and share your struggles.
- Others will find it difficult to start a conversation about your hearing loss. Acknowledge it is different for you – and talk about it. Approaching these topics with humour can also help.
- Advocate for yourself. Be open and honest about what you need. You'll be surprised by how others are open to new solutions.
- If it doesn't feel right in the beginning – it's not the right place for you.

It's no surprise that Sandra is purpose-driven. Before Ctalents, she built a successful café

business that only employed people with hearing loss. Orders could only be placed in sign language (a video in the café provided instructions).

Sandra's focus now is squarely on workplace change. About 50% of the agency's efforts focus on workplace education, accessibility and culture shaping. And Sandra says candidates themselves need support to overcome a lack of confidence and perceived barriers.

"Think about it, talk about it and plan it. This can also be an eye opener for a lot of other people in the office. It's time to rethink the workplace," she says.

"And find your confidence."

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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.

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COCHLEAR – Rose's tips for thriving in social situations



What would you do if someone told you to take off your sound processor because it wasn't "pretty"? For Rose, a model in France, this experience spurred her to create an online

community and inspire others to advocate for themselves.

"When I saw how many people were interested in deafness, I started making funny videos to portray situations I experienced every day. From there a community was created and continued to grow. More and more people told me that it helped them accept themselves, so I continued."

Rose was a National Ambassador for Cochlear Foundation's Achieve anything program. She has also written a book to help others: *Vivre avec une surdité: Un témoignage saisissant - Des conseils concrets* (Living with Deafness: A Striking Testimony – Practical Advice).

Some tips from her book:

Socialising in noisy bars, restaurants and nightclubs:

"When you go out with friends, whether it's for dinner, drinks or out somewhere at night where it's noisy, I recommend bringing a trusted friend with you. They can help explain the context of conversations that I'm struggling to follow."

During face to face conversations

"Position yourself strategically in front of them to help you lip read. Use your smartphone or a microphone to use direct streaming to help hear people more clearly."

When you're meeting new people

"If there are people you don't know at a meal or party, don't hesitate to tell them that you're hard-of-hearing or deaf. This will avoid the stress of answering them inappropriately or ignoring them. They'll understand!"

Rose feels like she's in a good place and continuing to advocate for people with hearing loss. *"I've completed my master's in luxury and retail, and now I work on raising awareness in companies to make their communication more inclusive. I plan to expand my social media community and start my own business."*

You can follow Rose on [Instagram](#) and [TikTok](#) @-rosepaynl

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MED-EL – BEATS OF COCHLEA: A DECADE OF CELEBRATING MUSIC AND HEARING TECHNOLOGY



(The Beats of Cochlea photo is courtesy of Kajetany Institute of Physiology and Pathology of Hearing.)

The Beats of Cochlea festival is a unique celebration that shines a spotlight on the musical talents of individuals with cochlear implants. Held from July 10 to 12, 2024, in Warsaw, Poland, this year's event marked the festival's 10th anniversary. Founded by the renowned Polish CI pioneer Professor Henryk Skarżyński, the festival highlights how music and technology can help people with hearing implants pursue their dreams.

This year, over 100 musicians from around the globe submitted their performances online. Among them were a dozen MED-EL cochlear implant users who proved that hearing loss is no barrier to musical expression.

Among the six finalists selected for the gala concert to play alongside the Polish Radio Orchestra was thirteen-year-old saxophonist and MED-EL user Matvey Romanovskiy, who shared his joy: "The wonderful atmosphere, such rehearsals, and performances on a stage with so many spectators are something I have never experienced before. It was a significant experience for me and has inspired me to aim for even greater heights!"

Aigerim Tutova, a MED-EL user and professional wedding singer, was invited as Prof. Skarżyński's special guest. Being both a singer and speech therapist, she covers different aspects of a musical life with cochlear implants.

Pianist and MED-EL user Ana-Maria from Romania performed at the first Beats of Cochlea festival and again at the 10th anniversary. It was fantastic to see her progress in both her hearing and musical performance!

A major part of the event was the "Art in Therapy, Medicine, and Science" conference, where experts discussed the role of music in developing hearing and speech, especially for cochlear implant users. The festival also featured interactive workshops, letting participants explore sounds through singing, dancing, and playing instruments. Relive the moments at Beats of Cochlea 2024 by exploring the [picture gallery](#)!

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[MED-EL – Hearpeers Hearing Journal](#)



Discover the steps back to hearing!



When someone is diagnosed with hearing loss, it can be a challenge to receive so much new information about hearing loss and implants.

That's why Hearpeers has created the Hearing Journal – a clear guide to help hearing implant candidates navigate their hearing journey.

With information on hearing loss and hearing solutions, readers are led through the basics of hearing loss to the different types of hearing solutions.

A detailed section on the hearing journey provides a comprehensive overview of each step one can expect to encounter on their way to a hearing implant. From diagnosis and timing to audio processor fitting and rehabilitation, readers can find essential information about each step. Hearpeers Mentors – volunteers trained to share their hearing implant story with others – also give supportive statements throughout the whole journey.

The Hearing Journal also contains a detailed set of FAQs to help candidates scan through common questions they may have. There is also a dedicated space for users to keep track of their notes for a Hearpeers Mentor or a hearing professional.

Download and share the Hearpeers Hearing Journal and find support for every step of your hearing implant journey.

Hearpeers is MED-EL's international community for all people united by the hearing implant journey.

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