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[Message from the President](#)



(Photo: Prof Graeme Clark and Robert Mandara)

In November, I was very happy to represent EURO-CIU with Sari Hirvonen-Skarbo, at the European Day of Persons with Disabilities (EDPD) in the European Commission. You can read Sari's report in this newsletter. In this EDPD we forged stronger links with other hearing loss organisations.

At the EDPD someone mentioned that “Accessibility should be accessible”. That sounds obvious but, in recent weeks, it has become clear that T-coils for use with induction loops have been quietly discontinued from almost all new CI processors, and also from many hearing aids. EURO-CIU does not support this move. Now we have a crazy situation where public buildings have to be equipped with induction loops for accessibility, but manufacturers are preventing their practical use! We call on all hearing instrument manufacturers to reinstate T-coils to their devices and also to have them enabled by default. Some CI users use T-coil a lot, for example to access church, theatre and counter services. Induction loops are simple and reliable technology that has been around for 50 years. There is a false expectation that Auracast, when it eventually comes along, will replace T-coils. However, EURO-CIU expects that T-coils and Auracast will coexist for some time at least, because each solution has pros and cons.

In this newsletter you can read about our next Symposium and General Assembly in Istanbul. Please note that there will be elections for Secretary (Pieter is standing down) and for second Vice-President. It is vital that we fill these roles. If you are interested to join the board and spread your CI advocacy wings, please contact any existing board member for more information.

As this year draws to a close, my Christmas came early! I had the great pleasure to briefly meet Professor Graeme Clark in Melbourne. He’s a very nice and humble man, still very excited about how technology such as AI will change CI in the future. I said to him that, as an electronic engineer, it never ceases to amaze me how much we can understand from just 22 electrodes. His response: “Me too!”.

With warmest wishes for the festive season and a productive 2025.

Robert Mandara
President

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



From our small village in the English Midlands, which some of you have visited, we wish you all the very best for Christmas and the New Year.

Many thanks to those who have sent us articles for this edition - 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 March, so please let me have your articles and jpg photos by Monday 3 March 2025. Just e-mail them to me at newsletter@eurociu.eu

With every good wish for Christmas and the New Year.

Brian Archbold (Editor)

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EURO-CIU – 30th Anniversary and 15th Symposium



The poster features the EURO-CIU logo (European Association of Cochlear Implant Users o.s.b.l.) and the CID Türkiye logo (Cochlear Implant Derneği) at the top. The central text reads "EURO-CIU's 30th Anniversary" in a stylized font, followed by "15th EURO-CIU Symposium Past, Present and Future: The journey of listening with cochlear implants". The dates "4th April 2025 Symposium" and "5th April 2025 General Assembly" are listed below. A registration link "Register here: www.eurociu2025.com" is provided. The location "ISTANBUL/TÜRKİYE Faculty of Architecture-TAŞKISLA" is highlighted in a dark blue box. The bottom left shows the hashtag #eurociu2025 and the website www.eurociu.eu. The bottom right features logos for İTÜ and the Faculty of Architecture-TAŞKISLA, along with a large image of the Galata Tower in Istanbul.

SAVE THE DATE!!!

It is a pleasure and great honour to welcome you, on behalf of Cochlear Implant Derneği (Cochlear Implant Association), CID Türkiye, to **EURO-CIU's 30th Anniversary and 15th EURO-CIU Symposium, Past, Present and Future: The Journey of listening with cochlear implants, in Istanbul**. It will be held in İstanbul, Türkiye on **4th (Symposium) & 5th April (General Assembly) 2025**.

Türkiye has been a centre of excellence in cochlear implantation for decades, with leading experts advancing ground-breaking practices in both paediatric and adult cochlear implantation. Since the inception of cochlear implant programs, the Cochlear Implant Association has played a critical role in providing information among families and building bridges between families and professionals.

We are honoured to once again host the 15th EURO-CIU Symposium, marking an important occasion for the cochlear implant community in Türkiye. This event provides a unique opportunity to demonstrate the advancements in cochlear implantation over the past three

decades and the profound impact these have had on the lives of individuals with hearing loss and their families.

Istanbul is an ideal location for this gathering, offering excellent travel connections to major European and international hubs, and world-class conference facilities designed to accommodate the diverse needs of a global event of this scale.

The website registration will be open starting from **15th January 2025** and current developments and information can be followed on the website, www.eurociu2025.com.

We look forward to hosting you and our colleagues in Istanbul, a city known for its rich history and ongoing contributions to the field of cochlear implantation.

Aylin ÖZGÜR,
President of CID Association

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[EURO-CIU – General Assembly 2025](#)



Following on from the Symposium in Istanbul will be the General Assembly on 5 April, and further details will be sent to members.

In 2025 we need to elect a new Secretary and a Second Vice-President. Please consider whether you are willing to apply. The Job Descriptions and the Application Forms can be obtained from our current Secretary, Pieter Bolle Pieter pieterbolle@gmail.com

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[EDF – Disability Day 2024](#)



The annual conference 2024 'European Day of Persons with Disabilities' took place in Brussels. The conference is part of the EU's wider efforts to raise awareness and tackle everyday challenges faced by persons with disabilities, in line with the UN Convention on the Rights of Persons with Disabilities and the EDF Strategy for the rights of persons with disabilities 2021-2030.

These two days of thought-provoking and engaging debate marked the International Day of Persons with Disabilities. The event brought together people from a wide range of backgrounds with different expertise and stories to share, including policymakers, high-level experts, representatives from several institutions and disability advocates. It gave to us, EURO-CIU president Robert Mandara and me (representing EURO-CIU as an EDF Board member), Sari Hirvonen-Skarbö, the opportunity to focus on networking and to share information. This was important when the new European Parliament and the new European Commission is to be put in place

The conference presented an opportunity to have an in-depth forward-looking discussion on the strategic objectives, policy proposals, and initiatives for the next five years. There were panel discussions on various topics related to all eight priority areas of the Strategy for the rights of persons with disabilities such as employment, independent living and transport.

I had the opportunity to ask a question about the women with disabilities having rights to live independently and persons with hearing loss to have rights to get the assistive listening aids like inductive hearing system in housing.

Access City Award

As is now a tradition, the conference included the ceremony of the Access City Award contest and celebration of its 15th anniversary. This contest was to reward EU cities making outstanding efforts to become accessible for persons with disabilities. The winners were cities from Austria Wien, Germany Nurnberg, Spain Cartagena, Sweden Borås. At the panel session, questions discussed accessible transportation, and I asked a question on the importance of notice board in public busses. When not hearing the announcements of bus stops, it is important to see the name of next stop.

Open letter sent to new Commissioner

On the International Disability Day, EDF sent an open letter from one hundred disability organizations, among them EURO-CIU, to Commissioner Hadja Lahbib, European Commissioner for Equality: Preparedness and Crisis Management. Together, EDF urged her to commit to advancing disability rights by updating the EU Disability Rights Strategy.

In the letter is stated that there are over one hundred million persons with disabilities living in the EU. Only 29.4% attain a tertiary degree compared to 43.8% without disabilities. Only 50.6% of men and 45.9% of women with disabilities are employed, often in part-time or low-paid jobs. It was noticed that, during the last mandate under the leadership of the first-ever Commissioner for Equality, good progress was seen in asserting disability rights. This was assured by the adoption of the EU Strategy for the Rights of Persons with Disabilities 2021-2030; and led to important achievements, such as the adoption of the European Disability Card and Parking Card.

Disability rights week celebrated also at European Parliament

The European parliament celebrated its second Disability Rights Week on the week from 2 to 6 December. Members of the European Parliament discussed the rights of persons with disabilities in a series of events that looked at a wide range of topics such as Artificial Intelligence, Women's Rights, and the need to ensure disability inclusion in EU. At the Employment Committee, there was discussion about the high drop-out rates of children with disabilities in inclusive education settings, and the lack of adjustments employers make for their employees with disabilities, even in the public sector. There is also the importance of making training/apprenticeships and entrepreneurship accessible to persons with disabilities to facilitate entry into the open labour market.

During Disability week, the Genders Equality Forum featured a photo exhibition "See Us for Who We Are – Women and Girls with Disabilities". The Exhibition was organized by EDF and was shown to the new EU Commissioner for Equality, Commissioner Hadja Lahbib. EDF made a presentation to her about issues faced by women with disabilities in the EU and the importance of including their rights and perspectives. One of the exhibition pictures is of the young woman using a cochlear implant. She and a classmate said: "They've come to realize that nothing can hold you back in life when you pursue it with passion!"

Sari Hirvonen-Skarbö (Finland), is the EDF delegate representing EURO-CIU

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[EDF – The European Disability Forum Board meeting in Madrid](#)



At the beginning of November, the European Disability Forum Board met in Madrid. The event was kindly supported by CERMI (the Spanish Committee of Representatives of Persons with Disabilities), and the ONCE Foundation.

Encouraged by the President of the European Disability Forum, Yannis Vardakastanis, a moment of silence was kept, remembering the catastrophe of the previous week's flooding in Valencia. He stated in his opening speech that the climate crisis is with us, and we don't know where it will hit, affecting people with disabilities. Infrastructure, roads, houses can be brought back, but human life cannot.

The conference consisted of presentations and panel discussions of 27 European Union countries. Presentations gave examples of the Constitutions of France, Spain and Croatia, studying whether it included (or not) the expression or the word of disability. Constitutions should include better options for implementing the UN CRPD in all countries, ensuring equality among the citizens with and without disabilities.

The Climate change is reality, as it affected Valencia, where EURO-CIU held its AGM in 2022. ONCE Foundation presented the fact that the impact of climate change for disabilities is enormous. Most of the time when there is disaster, persons with disabilities are firstly not informed. No system is tracking and detecting where people are living, and where they are. People with disabilities are left behind within the dialogue of climate policies, as well as in the preparedness.

CERMI Women Foundation was created 10 years ago, to work towards the rights of women and girls in all of Spain. President Conception Diaz noticed that nowadays society is witnessing everyday hatred speeches against diverse groups, LGBT, migrant minorities and persons with disabilities.

Nothing without us

At the Board meeting, stressed the need to include a disability perspective in national disaster risk reduction and preparedness plans.

The Board discussed the ongoing draft of the EDF Strategy 2025-2030 "Nothing without us – Joining forces for a disability-inclusive Europe", which will be launched in January. The strategy is divided into eight chapters that cover different areas where the EU aims to improve the lives of persons with disabilities, the last of which focus on how to deliver the strategy in practice and measure its impact. These are:

1. Accessibility – an enabler of rights, autonomy and equality
2. Enjoying EU Rights
3. Decent quality of life and living independently

4. Equal Access and non-discrimination

The “flagship initiatives” are like laws that will have a stronger long-term impact. The first one is interesting – Disability Employment and Skills Guarantee, which is aimed at Youth. The second is European Agency for Accessibility, which will be based on building the work of the Accessible EU centre. The third is the legislation on the affordability of assistive technology. The legislation is to guarantee the availability and affordability of assistive technologies for persons with disabilities in the EU single market, building upon the investigation carried out by the Commission in 2024.

EDF resolution: Right to offline access to essential services. “Everyone has the right to access essential services of good quality, including financial services and digital communications.” Noticing that services are moving online, it is happening despite the fact that over 40% of the EU’s population lacks digital skills and access. Approximately 1 in 5 citizens of over 65 years of age, lack access to technology or digital skills. EDF calls on the EU and Member States to adopt European Union-wide legislation which ensures essential services of public or private sectors.

For the new elected Parliament members, it was updated on the campaign to re-establish the European Parliament’s Disability Intergroup: meeting participants were asked to reach out to Members of the European Parliament and urge them to join the Intergroup.

Sari Hirvonen-Skarbö (Finland), is the EDF delegate representing EURO-CIU

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EDF Photo Competition 2024 – Through the accessibility lens: Stories of barriers, challenges and good practices



EDF Photo Competition 2024

Through the accessibility lens:
Stories of barriers, challenges and good practices



Accessibility goes beyond ramps and elevators – it’s about removing barriers in every area of life, from physical spaces to digital platforms and inclusive communication. True accessibility means ensuring everyone can participate fully and independently.

However, for many persons with disabilities, life is a mix of barriers, challenges and triumphs, navigating a world that often overlooks their needs.

EDF is inviting photographers, both amateur and professional, to participate in our Photo Competition focusing on accessibility and the daily challenges faced by persons with disabilities.

Capture moments that highlight the barriers, solutions, and personal stories related to accessibility and the experiences of persons with disabilities.

Whether it's a portrait, a streetshot, or an innovative approach, your photographs and their stories can inspire change and raise awareness. Participate!

Deadline for submissions: 30 March 2025

Prizes

The three final nominees will receive:

- 1st place award: 500 euros
- 2nd place award: 300 euros
- 3rd place award: 200 euros

For further information, [please click here to visit the website](#).

Sari Hirvonen-Skarbö (Finland), is the EDF delegate representing EURO-CIU

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AUSTRIA – CIA – The CIA board is getting younger and younger!



Unfortunately, our long-time chairman Karl-Heinz Fuchs was absent from this year's CIA Christmas party: After many years of dedicated work in the self-help group, he stepped down from his position for health reasons. Hans Horak, who has been Karl-Heinz's "right-hand man" for many years as deputy, was confirmed as the new managing chairman at the general meeting. His deputy is Markus Fraisl, who has been actively involved in the club's management for several years. At the same time, some other board members have also changed. Particularly noteworthy: Offers for children and young people will continue to be managed by Stefan Obermaier, but now together with the 18-year-old bilateral CI user Melanie Fraisl. Melanie has already been actively involved in the EURO-CIU meetings twice. With her, the average age of the CIA board is significantly younger again. 😊

We sincerely thank Karl-Heinz for his 31 years of active work with the CIA and for his dedication. He was unanimously appointed "Honorary Chairman for Life" by all those present, and the two chairmen and Hilde Renner jointly visited Karl-Heinz and presented the certificate. We wish Karl-Heinz many happy years as honorary chairman! Hopefully, we will see him at one or another CIA event in the future. At the same time, we are pleased that Melanie will bring even more youthful energy to our group. Together with Alexander and Matthias Pusker, she now forms the young triumvirate of the CIA. We wish her and all the other new board members much joy and success in their tasks!

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[AUSTRIA – ÖCIG held its symposium in Vienna](#)



On October 5, 2024, the Austrian Cochlear Implant Society ÖCIG held its symposium in Vienna – a great event for professionals, affected people, and interested parties. It was a chance to learn about the latest developments regarding cochlear implant technology and also the challenges and opportunities that arise with rehabilitation.

The symposium represented a broad and complex agenda of the most pressing issues concerning speech therapy and rehabilitation post-cochlear implantation. In Austria, the post-implantation complex rehabilitation process is highly underestimated. Speech therapy is an especially important area since it guides the patients through their new auditory world and helps develop their communicational skills. Professional speakers emphasized that different patients had different needs and thus required different kinds of therapy.

The symposium also featured very enlightening presentations by experts from different fields who presented the latest research and development in cochlear implants. One of the interesting topics was on the innovative approaches to speech therapy, which showed how modern technologies and interactive methods can make the rehabilitation process much easier. Another captivating presentation dealt with the psychosocial aspects of rehabilitation, which in many cases are crucial for the long-term success of an implantation.

Personal testimonials added a deeply human element to the programme. Thus, Kateryna Luhova, a refugee from Ukraine who received a cochlear implant in Austria two years ago, shared her story in German. And a live link to Djerba, where Sarah Felten discussed her self-help group in Germany and a school for the deaf in Djerba. Particularly worthy of mention is the presentation of Martin Schaarschmidt's book "Hör Pioniere – Wie das Cochlear-Implantat nach Deutschland kam" by its author. The accounts moved the audience emotionally and provided a valuable look at the daily lives of those affected and the importance of professional support.

The symposium of ÖCIG was, however, more than only an informative event; it was a place of personal exchange and inspiration. This underlined the importance of combining all the stakeholders in the area of cochlear implants from doctors and speech therapists down to the affected persons themselves, who can best support one another.

In all, the symposium was a huge success and an important step toward greater awareness of the need for speech therapy and rehabilitative support after cochlear implantation. The ÖCIG is thus sending a clear message about the future of hearing rehabilitation in Austria: further investment in research and practice will be needed. We look forward with enthusiasm to the new insights and advances that this stimulating exchange will bring.

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[GERMANY – DCIG – The Bavarian Cochlear Implant Association \(BayCIV\) – Bavarian Constitutional Order 2024](#)



The Bavarian Cochlear Implant Association e.V., is delighted that our first chairwoman Regine Zille has been awarded the Bavarian Constitutional Order 2024 by State Parliament President Ilse Aigner.

A press release and a picture of the award ceremony (image copyright Matthias Balk/Image Archive of the Bavarian State Parliament) are as follows:

Munich, December 5, 2024

As part of the award ceremony for the Bavarian Constitutional Order 2024, Ms. Regine Zille was honored for her outstanding commitment to people with hearing impairments.

The award underlines the importance of her years of work and her tireless commitment to the concerns of those affected. Regine Zille from Garching, 1st chairwoman of the Bavarian Cochlear Implant Association, has made a special contribution to improving the living conditions of people with cochlear implants. She is the founder of the Hearing Impairment Network Bavaria, she coordinates the work of 35 self-help groups of the BayCIV in Bavaria and she is involved in the disability advisory boards in Garching and the Munich district.

She impresses with her tireless commitment to effectively asserting the needs of hearing-impaired people in politics and society. In addition, she organizes training courses and seminars for affected adults and families with hearing-impaired children, thus providing great and human support.

By awarding her the Bavarian Constitutional Order, the Bavarian State Parliament is honoring her extraordinary commitment and tireless efforts for an inclusive society. Ms. Zille's work has helped to raise awareness of the concerns of people with hearing impairments and significantly improve the quality of life of those affected. State Parliament President Ilse Aigner in her laudation: *"Today we are highlighting the best in our society: the successful, the positive, the communal!"* One motto runs like a thread through Regine Zille's voluntary work: *"Confidently communicate without barriers."* She has dedicated herself to this guiding principle for many years in her extensive voluntary work for people with hearing impairments.

About the Bavarian Constitutional Order: The Bavarian Constitutional Order is awarded by the Bavarian State Parliament to citizens who have made a special contribution to the

implementation of the principles of the Bavarian Constitution.

<https://www.bayciv.de/news/regine-zille-mit-bayerischem-verfassungsorden-ausgezeichnet>

<https://www.bayern.landtag.de/aktuelles/auszeichnungen/verfassungsorden/verleihung-der-verfassungsorden-2024/>

Reinhard Zille

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THE NETHERLANDS – OPCI – Meeting Day of OPCI Foundation in 's-Hertogenbosch



(Photos: clockwise from top-left: Dennis Massar, Mirjam Stolk, Hennie Epping, Maartje Hendrikse and the new logo)

OPCI turns from a platform into a Foundation – 5 October 2024

Setting up and welcome

This meeting day took place at De Verkadefabriek in 's-Hertogenbosch. By half past ten, I walked into De Verkadefabriek. Some volunteers had already set up the space for the meeting day and the exhibitors had set up their tables. The registration table was also ready to receive our visitors. Gradually, the audience came in. In total, there were almost 150 visitors.

Opening

Hennie Epping, president of OPCI, opened the day at 11 o'clock and first of all explained that OPCI had become a foundation. In the year 2005, OPCI was founded for hearing-impaired and deaf people who all had something to do with a cochlear implant. Because these people were

with different organisations for a while, there was a mixture of knowledge about cochlear implants. To pool the different knowledge levels, OPCI was established, a platform of hearing-impaired and deaf people from different organisations. Collaboration with these organisations has continued. These organisations still come to OPCI, the central place in the Netherlands for everything related to Cochlear Implantation, with all kinds of questions about the CI. The OPCI platform was not a legal entity, but certainly wanted to become one. Various forms of governance for this were under scrutiny, but in the end OPCI chose a foundation. That deed was signed in July 2024, and from then on OPCI is officially a foundation. The audience witnessed the unveiling of the new OPCI logo.

Henk van Rees, secretary of OPCI, talked about the activities of the OPCI Foundation, such as information, advocacy and lots of room for contact with fellow-ci users, including many small-scale “living room” meetings, in which CI wearers and candidate CI wearers talk to each other. He also says there will be another contact day in Nijkerk on 8 March 2025. OPCI also conducts periodic visitations to all CI teams. Visitation means that they are assessed by colleagues from other hospitals, look at whether protocols are being followed, but also whether there are any problems and whether the organisation is sound. That is where OPCI makes its contribution.

OPCI consists entirely of volunteers. There are currently seven volunteers, but they are always looking for new volunteers because a lot of work is done at OPCI.

Theme

The theme of this day was Music connects. This theme was elaborated by bilateral CI wearer and teacher/dancer Dennis Massar at the music academy in Arnhem and Mirjam Stolk, music interpreter and known for translating and singing many songs in sign language. Mirjam was not present herself, but had made a beautiful film for OPCI especially for this meeting day.

Besides the theme Music connects, a hearing simulator was presented by Maartje Hendrikse, scientific researcher at Erasmus MC in Rotterdam.

Film by Mirjam Stolk

Mirjam Stolk is a Dutch Sign Language interpreter specialising in music interpreting and the translation process. She has been working for 20 years. She believes that making music and dance visual can add value for deaf and hard-of-hearing people. To make that happen, she was involved in a sensory festival Sencity after getting her degree. She had been deployed with the bands performing there to make them accessible to deaf and hard-of-hearing audiences. That way, she had kind of rolled-in, posting some videos on YouTube. All her passions were together: sign language, music and dance, and working as an interpreter.

In this film, Mirjam explains her working method in detail, especially with her rendition of Joost Klein's song Europapa, which made her even more famous. That song and her working method can be seen extensively on the film. Music in gestures and Mirjam's enthusiasm, made this film great fun, the audience got excited.

Virtual Reality Hearing Simulator

Scientific researcher Maartje Hendrikse and fellow researchers in collaboration with some experts by experience are designing a Virtual Reality Hearing Simulator. This simulator is still under development. The purpose of this simulator is to ensure that hearing-impaired people take hearing impairment into account more thoroughly, to identify the problems that hearing-impaired people encounter and to provide tips on how difficult situations can be solved with better communication. Another goal is to increase hearing people's understanding of what it is like to use hearing aids and also experience what it is like to hear with a cochlear implant and what the challenges of CI wearers are. For this purpose, separate simulations are made for

hearing aids and for CIs. Maartje explains how these simulations are researched and made in different listening situations.

Three target groups have been defined for this simulator: firstly, the relatives of hearing-impaired people, i.e. partners, family and friends. By letting them experience hearing impairment, they will be better able to cope with it and we hope there will be less frustration. The second target group is healthcare providers and educational staff, hoping to increase their understanding and better deal with their hearing-impaired patients or students. And third: the general public.

Finally, visitors could put questions to Maartje. This session was widely used.

Lunch break and discussion corners

During the lunch break, participants had the opportunity to visit the stands and get information from CI or device manufacturers. And, of course, to spend a long time talking to each other.

Presentation by Denis Massar

Dennis Massar, bilateral CI wearer and teacher of dance in Arnhem, had meningitis at the age of two, which left him deaf and with one CI. First of all, Dennis encouraged people from the audience to ask questions. A lot of use was made of this. Then he talked about his own 'hearing journey' and music.

When he was young, he did a lot with music as a training. At the age of 11, he was taking drumming lessons, an important basis for musical rhythm. That was the beginning of all his music activities. He also did street dance, had been a DJ, a course in making digital music on a computer. From the latter, he also gained musical knowledge of: how is music put together? What time signatures are there? Rhythms? What is music made of? As a result, he heard lots of types of instruments on the computer. At the age of 16, he started dancing with the knowledge gained. In 2021, he started at the ArtEz dance academy in Arnhem, where, apart from dancing, he also learned different kinds of music. With his story, Dennis enthused the audience about music and dance.

Closing

Henk van Rees thanked volunteer Ingrid Cuppen and writing interpreter Davy de Bruin and all those present. Hennie Epping then closed the meeting.

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

With this, OPCI Foundation looks back on a very successful day.

Henk van Rees

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[ROMANIA – Asculța Viata – When Waves Become Stories](#)

space to explore their creativity, refine their skills, and demonstrate that their presence in this world is unique and invaluable.

This year's edition featured an extensive format, including:

- an international collective exhibition in the WaveforMe virtual gallery,
- two podcasts,
- a creative camp held in Romania, and
- an experimental film, "Wave's Imprint", created with international participation.

The project brought together **53 participants from 20 countries**, including Romania, Moldova, Spain, Estonia, Croatia, Belgium, England, Turkey, Iran, the Philippines, Poland, Greece, Japan, Italy, Hungary, the Netherlands, China, Serbia, Mexico, and the USA. Each of them left their mark – one that is visible, authentic, and deeply meaningful.

One of the central elements of "Wave's Imprint" was the courage to use art not just as a form of expression but as a tool for change. During the creative camp held in Romania in July, participants were encouraged to collaborate in shaping the film's structure, drawing inspiration from ideas and themes they generated themselves. The process was carefully guided by the project team, helping each participant overcome fears like "maybe it's not good enough."

For international participants, the connection was established through personalized emails, culminating in a symbolic gesture: a handwritten letter sent via post. Many revealed that it was the first time they had received such a personal message, a detail that, unexpectedly, added profound depth to their creative experience.

The project offered these young people the opportunity to (re)discover their self-confidence and uniquely explore their inner voices. At the same time, it provided everyone involved with a valuable lesson about overcoming barriers and bridging distances, creating together a space dedicated to connection and creative expression.

The final event, held on November 2, marked the pinnacle of the project, filled with emotion and excitement. It was an opportunity to reunite some of the young people who had played an essential role in shaping this collective story.

The event showcased a physical exhibition of works from the virtual gallery and the film screening. A particularly special moment was when participants selected a piece from the exhibition and physically removed it from the wall themselves – an action that became a performance in its own right. This symbolic gesture was deeply appreciated by both those present and the exhibiting artists. Artists who could not attend received photos from the event, immortalizing those moments. It was a powerful confirmation of their personal and artistic value.

These words capture the spirit of an initiative that turned individual experiences into meaningful collective stories:

"It's so moving to see our work come to life and resonate with the audience."

"I'm so happy to know someone appreciates my work. The whole process was wonderful. I've learned to appreciate life, enjoy the little things, and be present. No matter how dark the world seems, there's always light at the end of the tunnel."

"Wave's Imprint" is not just about those directly involved; it's about all of us. It's a lesson in seeing beyond limitations.

This project has shown that art not only reflects the world but profoundly influences it, driving significant and lasting change.

We invite you to discover the world of "Wave's Imprint", with all the experiences and creations brought to life in this and previous editions, on the platform www.waveforme.org.

This project would not have been possible without the support of the National Association of Romanian Hearing Impaired Persons, "Hear Life!", Impuls Leasing Romania,

and the partners:

Audiosofia (NGO), Koala Auditory-Verbal Rehabilitation (NGO), Perspectives for Hearing-Impaired Children (NGO), The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH), Immigration Research Forum Washington D.C., the European Federation of Parents of Hearing Impaired Children (FEPEDA), Life Long Hearing.

Cultural Project Funded by the Romanian Ministry of Culture.

Vero Nica – artist & cultural project manager

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SPAIN – AICE – 1 October, World Day of Older Persons



Congress hosted the presentation of the platform 'Ser Oído' (Be Heard) for better access to cochlear implants for older people with profound hearing loss

The 'Being Heard' initiative, promoted by the Federation AICE (Spanish Federation of Cochlear Implant Associations), is committed to a better future for older people with profound hearing loss. The platform, which was presented on 1 October at the Spanish Congress of Deputies with almost 200 attendees, including more than 100 cochlear implant recipients and their families, seeks to raise awareness of the need to build a more inclusive, accessible and

sustainable future for people with profound hearing loss, as well as to improve access to cochlear implantation for the elderly population.

The event included a speech by the head of hearing at the WHO, Dr. Shelly Chadha, and a round table moderated by journalist Ana Blanco, with the participation of Dr. Serafín Sánchez, vice-president of SEORL (Spanish Society of Otorhinolaryngology), Dr. Carlos Cenjor, otorhinolaryngologist and president of the GAES-Amplifon scientific committee, and Inmaculada Soto, president of the Federation AICE. The event was attended by more than 100 cochlear implant users from different parts of Spain, many representatives of the Congress and Senate from all political parties, who have committed themselves to pass on our proposals and agree on how to achieve them, as well as otolaryngologists, audiologists, nurses and speech therapists.

The event celebrated on the World Day of Older Persons was covered by numerous media (written and digital press, radio and television), and has had a great impact on social networks.

The challenges of ‘Being Heard’.

Joan Zamora, spokesperson for the campaign, presented five key pillars: awareness raising, better data, comprehensive screening, research and equitable access. The Federation AICE’s initiative, with the collaboration of GAES-Amplifon, seeks to counteract these factors that hinder access to cochlear implants for the elderly. One of its objectives is to raise awareness among both health professionals and society to combat the stigma associated with hearing loss and its denial. In the same vein, it aims to promote early detection and treatment with sustainable funding to ensure more equitable access for all patients.

Already 79 organisations, including other big Spanish patient associations, professionals and medical and scientific societies, have signed up to the ‘Being Heard’ manifesto. The platform also has broad popular support, with more than 2,500 signatories. Please join our campaign: <https://www.seroido.org/>

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[SPAIN – AICE – Annual Meeting of young cochlear implant users](#)



On 15th and 16th November, the Federation AICE held its annual meeting of young CI users in Barcelona. About thirty young people between 18 and 33 years old from all over Spain participated in this meeting.

This year's Youth Meeting was a success and sold out, surpassing all expectations. Thirty young cochlear implant users were able to enjoy different workshops and talks, all of them accessible thanks to simultaneous transcription. The event combined recreational activities, educational workshops and accessible cultural experiences to promote learning and coexistence among young cochlear implant users.

The event began with dynamic presentations, followed by workshops such as the use of Meludia to work on hearing through music and a participatory analysis of the Federation AICE website. In addition, a panel discussion highlighted stories of overcoming challenges, showing how cochlear implantation is not a limit to achieve professional and personal goals.

The conference included dynamics such as SWOT analysis, talks on the European Youth Event 2025 and a workshop on volunteering and visibility in the magazine Integración. The cultural experience was accessible visits to the Sagrada Familia and Palau Güell which were a success, showing the commitment to cultural inclusion.

The event culminated with the AICE Awards Gala, an emotional moment to celebrate achievements and strengthen ties.

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[RELATED CONGRESS – International Federation on Ageing](#)



International
Federation on
Ageing

a contribution to the
**Decade
of healthy
ageing**

Webinar

Increasing Cross Sectoral Collaboration in Advocacy Efforts for Ear and Hearing Care Services



16 January 2025



10 a.m. EST



Dr. Joshua Chodosh

Clinical Geriatrician and Professor
of Medicine and Population Health at NYU
Langone Health and NYU Grossman School
of Medicine



Dr. Kathy Pichora-Fuller

Professor Emerita of Psychology
at the University of Toronto
and Adjunct Professor of Gerontology
at Simon Fraser University



Dr. Sue Archbold

Co-Ordinator of the CI International
Community of Action, CIICA, and
Steering Committee, World Hearing Forum

Supported by Cochlear

Webinar: 16 January 2025, 10am EST, 16.00 CET

Increasing Cross-Sectoral Collaboration in Advocacy Efforts for Ear and Hearing Care Services

The International Federation on Ageing (IFA) has been carrying out a global project aimed at Increasing collaboration across sectors to advocate for Ear and Hearing Care Services. You are invited to a Webinar about the findings and hear about how cross collaboration can promote Ear and Hearing Services across the lifespan.

Register at:

[Zoom Registration Link](#)

[LinkedIn Post](#)

The United Nations (UN) Decade of Healthy Ageing calls for environments that foster healthy ageing and help to maintain and improve functional ability, including hearing health in later life. As reported by the WHO World Report on Hearing, globally, more than 1.5 billion people experience some degree of hearing loss, which translates to about 1 in 5 people, worldwide. By 2050, this number is anticipated to grow by 60% to 2.5 billion, which means that 1 in 4 people will experience hearing complications. This trend parallels the rapidly ageing global population. By 2050, the projected number of persons aged 60 years and older will double to 2.1 billion

people, and the subpopulation of those aged 80 years and older is expected to triple to an estimated 426 million individuals.

Amidst mounting evidence highlighting the critical link between hearing health and overall healthy ageing, numerous obstacles hinder older adults' access to essential ear and hearing care (EHC) services. The initiative Increasing Cross-Sectoral Collaboration in Advocacy Efforts for Ear and Hearing Care Services aims to empower civil society organizations (CSOs) and stakeholders beyond the realm of hearing health to effectively comprehend, engage with, and advocate for ear and hearing care services (EHC).

A comprehensive assessment of existing national aged care and dementia policies across six countries within the WHO regions, pinpoints existing gaps and opportunities that can be leveraged to support and encourage greater engagement and investment in this important issue.

Key areas of interest for the project include:

- prevention (raising awareness and knowledge and having strong national policies);
- access (understanding and addressing structural and modifiable barriers); and
- equity (timely and affordable EHC services for all, and targeted advocacy efforts).

Phases 1 and 2 have explored National Aged Care Plans and interviewed national and international Civil Society leaders. Phase 3 is the webinar to share the findings so far and to illustrate the relationship between hearing health and other key sectors.

Cochlear implantation in older adults is a growing area of interest and activity, and one we need all to consider; as the great initiative by AICE in Spain shows us.

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[RELATED CONGRESS – UK – BATOD and BAEA joint conference –
“Technology in our hands: changing the world with deaf children and young people”](#)



IN PARTNERSHIP WITH



EXMOUTH, UK
Saturday 22 March 2025

The British Association of Teachers of Deaf Children and Young People (BATOD) and the British Association of Educational Audiologists (BAEA), with support from BATOD South West and BAEA South, invite all interested parties (teachers, professionals, lecturers, researchers, developers and manufacturers of technical devices, service providers, service users, policy makers, students etc) to present their work.

Venue: [The Deaf Academy](#), 1 Douglas Ave, Exmouth EX8 2AU

BATOD and BAEA joint conference 2025 - early bird tickers available to 31st December

[Further information here](#)

Keynote speakers:

Opening presenter - Kellie Mote (JISC)

Closing presenters - Cheryl DeConde Johnson (Hands & Voices)

Call for contributions extended to 12 January 2025. Please send your proposals to Conferenceabstracts2025@batod.org.uk

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RELATED CONGRESS – USA – ACI Alliance – CI2025 Boston: Registration is OPEN!



Boston 30 April – 3 May 2025

Registration is open for the ACI Alliance CI2025 Boston Conference on Cochlear Implants taking place April 30 – May 3, 2025 at the Omni Seaport Hotel in Boston, Massachusetts. Dr. Nancy M. Young has been selected to deliver the annual Niparko Memorial Lecture at CI2025 Boston, on “Language Prediction to Improve Outcomes for Children with Cochlear Implants.” The Niparko lecture was established to recognize Dr. John K. Niparko’s enduring commitment to cochlear implant research and clinical care and honour his significant contributions to the field.

[Register Here](#)

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RELATED CONGRESS – USA – Twelfth International Adult Aural Rehabilitation Conference





Woburn, MA 4 – 6 May 2025

(Photo from previous conference and Geoff Plant)

If you are coming to Boston for CI2025:BOSTON, you should consider staying on for a few more days to attend the **Twelfth International Adult Aural Rehabilitation Conference** to be held in Woburn, MA. Woburn is located around 20 km (12 miles) from Boston, and there are a number of hotels near the conference site. The conference is hosted by the Hearing Rehabilitation Foundation (<http://hearingrehab.org>) and offers participants the chance to find out more about the current state of Aural Rehabilitation practices.

The theme of the Twelfth International Adult AR conference will be “Aural Rehabilitation: Where the Magic Happens!” We are calling for papers that embrace the theme of providing AR services of all types in the office/clinic and/or in the surrounding community. We welcome any papers on innovations in this increasingly important area. Please contact Geoff Plant (hearf@aol.com) if you would need to obtain a waiver of the submission deadline of November 28, 2024.

Our invited speakers are **Nicholas Reed** from New York University, and **Karen Chan Barrett** from the University of California, San Francisco. Nick will speak on the ACHIEVE clinical trial of hearing intervention vs healthy aging control on 3-year cognitive decline, and provide insights on hearing, hearing aid use, and aging outcomes from large epidemiologic studies such as National Health Aging and Trends Study. Karen’s presentation will focus on the use of music for aural rehabilitation. There will also be a number of contributed papers, plus a panel of adults with hearing loss speaking about the effects of auditory training on their lives.

The Conference will start with a reception at the HRF Office in Woburn, MA on the evening of Sunday, May 4, 2025. This informal event will run from 5:00 – 7:00 pm and will provide a chance to catch up with old friends, and to meet participants from other places. Transportation will be provided from local hotels if needed. The meeting will run for two full days (9:00 am – 5:00 pm).

Registration is now open, and we are offering an Early Bird fee of \$300 until December 31, 2024. The registration fee after this date will increase to \$350. The registration fee after March 28, 2025 will be \$400. This fee provides one conference registration, which includes light breakfast, lunch, morning, and afternoon coffee breaks on the two days of the conference, the Welcome Reception on May 4, 2025, and a copy of the Conference Handbook. A Conference Dinner is planned for the evening of May 5, but will not be covered by the registration fee. A special registration rate for students is available upon request.

WE HOPE TO SEE YOU THERE!

Geoff Plant

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[RELATED CONGRESS – International Symposium on Usher Syndrome](#)

INTERNATIONAL SYMPOSIUM ON USHER SYNDROME

19, 20, 21 June 2025 • Nijmegen, The Netherlands

ush2025.org

info@ush2025.org

#USH2025



Nijmegen, The Netherlands
19 – 21 June 2025

Save the date – USH 2025

- Registration open for the Scientific Congress (on June 19th-20th) of USH2025.
- As the Scientific Congress focuses on knowledge sharing and aims to connect and encourage collaboration and crossovers between different fields of expertise, you will be a great help if you can share this news with your network of interested researchers and scientists. And invite them to join us!
- Registration URL: <https://www.ush2025.org/en/informatie/inschrijven-en-kosten/>
- During registration participants can choose to submit an abstract for oral or poster presentation
- Abstracts to be submitted by March 28, 2025, the Abstracts Committee will send further details to the applicants
- More information about the Scientific Congress, such as fees, location, speakers, accessibility, can be found on our website. www.USH2025.org/en/

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RELATED CONGRESS – CI Advocacy in Action 2025: Advocating for sustainable, lifelong CI services globally



Brussels, Belgium 16 – 17 October 2025

WHEN: Thursday 16 October from 09:00 to 17:00 and Friday 17 October from 09:00 to 16:30.

WHERE: [Maison des Associations Internationales](#), 40 Rue Washington, Brussels, 1050 on 16th & 17th October 2025.

Registration Open 20 January 2025: [Please see website for further details.](#)

Our CIICA global network continues to grow, with members in 72 countries inspiring each other to action to ensure maximum benefit from this amazing technology.

Building on the impact of our first global conference in 2024, CI Advocacy in Action 2025 will bring together the network of CI users, families, professionals, academics, industry and policy makers and funders to share advocacy challenges and successes. With funding and resource challenges globally how do we ensure that those who could benefit from CI can gain access, and those who have CI have the lifelong services required?

How do we influence the key stakeholders? Could services be delivered differently? How can service providers and users and families work together to ensure the services are effective and efficient? What about equity for those in low- and middle-income countries? How are services delivered to those who are older?

These and other issues will be addressed in a lively and vibrant two days, in this unique inclusive conference learning from each other and international collaboration. Come and join us to add your voice to the network and help us move CI Advocacy forward across the globe!

EURO-CIU is a founding member of CIICA.

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[WORLD NEWS – CIICA produces new Advocacy Guide for Cochlear Implants.](#)

ADVOCATING FOR COCHLEAR IMPLANTS



(Photos from top-right: Anita Grover, Sarah Rubinelli and Carolina Der)

CIICA'S new Advocacy Guide is developing!

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.

CIICA has produced this guide 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. [CIICA ADVOCACY GUIDE](#)

As part of this, three advocacy videos are currently available with more to come!

Anita Grover:

How to influence Governments is crucial in advocacy campaigns for Cochlear Implants. Anita Grover, Chief Executive of Auditory Verbal UK and previously a Civil Servant with the UK

Government, outlines the key principles you need to be aware of to influence Government in your Advocacy work.

[Watch the video here.](#)

Carolina Der, WHO

Making sure that Cochlear Implants are affordable and accessible is crucial to ensuring wider access for all who need them. In this video, Carolina Der from the World Health Organisation explores these themes and what advocates can do to ensure wider access.

[Watch the video here.](#)

Professor Sara Rubinelli

Professor Sarah Rubinelli from the University of Lucerne, takes us through some of the core principles which we should consider when putting together an advocacy campaign. As she says advocacy is a marathon not a sprint!

[Watch the video here.](#)

EURO-CIU is a founding member of CIICA.

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WORLD NEWS – World Hearing Day 2025



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WORLD NEWS – The European Federation of Hard of Hearing People (EFHOH)



EFHOH wishes to congratulate our President Lidia Best on her appointment to the WHO Technical Advisory Group on Disability and Health (TAG-Disability and Health) by WHO Europe!

The President's commitment to disability rights and public health will play a crucial role in ensuring equitable and accessible healthcare for all, particularly by amplifying the perspectives of hard of hearing individuals during public health emergencies.

This is a remarkable achievement, and we are confident her contributions will make a lasting impact in advocating for inclusive health policies across the WHO European Region.

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[WORLD NEWS – Usher News & Highlights relevant for the CI Community](#)



ERN Eye Webinar on Usher Syndrome was held on Friday 29 November, 3.30 pm CET, and covered:

- Clinical aspects of Usher syndrome presented by Pr Katarina Stingl, University Tübingen, Germany.
- Disease progression of USH1B and Implications for Gene Therapy presented by Pr Francesca Simonelli, University of Campania Luigi Vanvitelli, Naples, Italy
- What is relevant for patients and their families presented by Dominique Sturz, ERN-EYE ePAG chair, looking into the patient perspective during the diagnostic & care pathway, into Do's and Don'ts in clinical settings and into science & research relevant to patients
- The recording of the webinar is available under this link: https://www.ern-eye.eu/type-media/videos/?_sft_categorie-media=webinars-replay

More ERN Eye USH Ressources are available at ERN Eye website <https://www.ern-eye.eu/#>

- ERN Eye Good practices series leaflet for professionals #2
- ERN Eye Educational video on USH
- eLearning program under development

- Clinical Practice Guidelines, Clinical consensus statements & Patient care pathways under development
- Clinical trial database (by disease)

European Reference Networks (ERNs) are a unique and innovative cross-border cooperation platforms between specialists for the diagnosis and treatment of rare or low prevalence complex diseases, such as syndromic hearing disorders.

Scientific Updates:

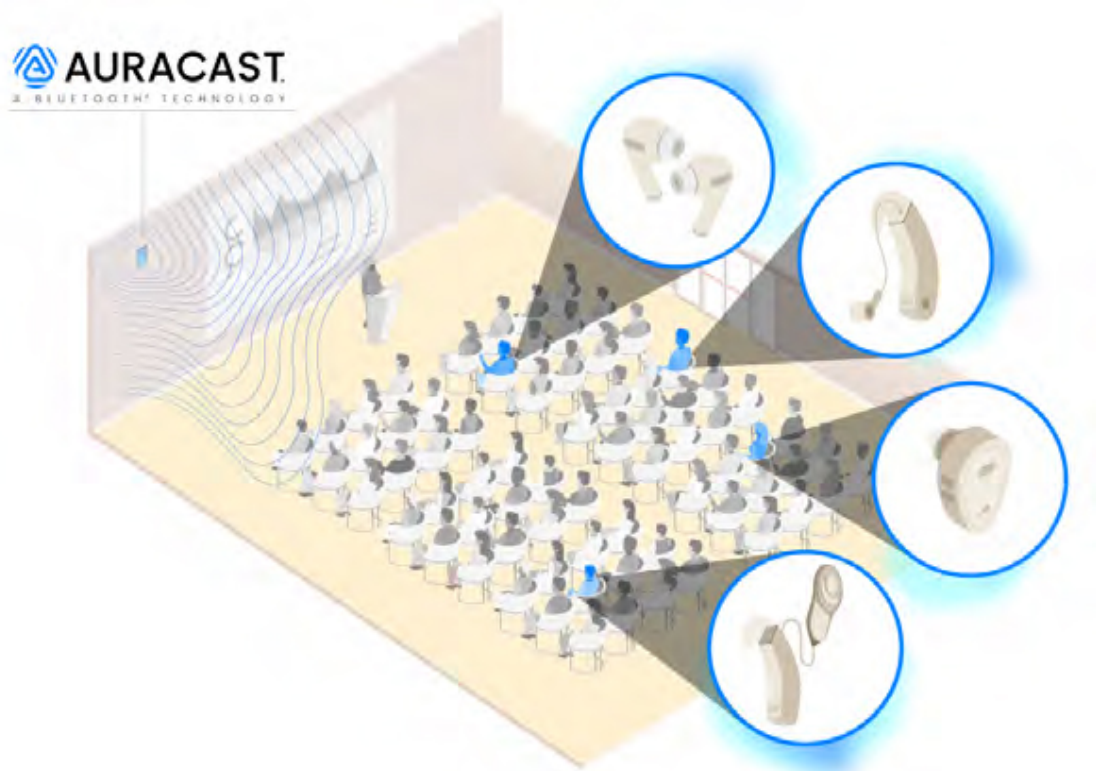
- Sepul Bio is re-initiating the Ultravursen program for USH2A Exon 13 mutation (former ProQR program), find more details here https://sepulbio.com/wp-content/uploads/2024/12/First-Patient-Dosed-in-LUNA_Press-Release_Dec12-2024.pdf and here <https://clinicaltrials.gov/study/NCT06627179?cond=USH2A&sort=StudyFirstPostDate&rank=1>
- AAVantgarde Bio recently have presented preliminary safety data about their AAVB-081 program for USH1B, find more information here <https://www.aavantgarde.com/en/news/aavantgarde-announces-oral-presentation-of-luce-1-clinical-study-at-floretina-2024/> and here <https://clinicaltrials.gov/study/NCT06591793?term=AAvantgarde&rank=2>

Dominique Sturz

Patient Advocate Usher Syndrome & Rare Diseases, Usher Initiative Austria

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WORLD NEWS – EHIMA – Auracast



Auracast™ broadcast audio, a new Bluetooth® capability, allows audio content to be streamed in digital stereo quality to multiple devices at the same time. Developed with the support of the European Hearing Instrument Manufacturers Association (EHIMA), this technology sets a new standard for accessible listening and improves the inclusion of people living with hearing loss.

Until now, Bluetooth® connectivity was limited to one transmitter and one receiver. By contrast, the signal from an Auracast™ broadcast audio transmitter can be received simultaneously by an unlimited number of devices using Auracast™ broadcast audio within its range. This is particularly beneficial for people with hearing loss who face challenges in public spaces.

This allows people with and without hearing impairments to receive audio content in digital stereo quality directly through their Bluetooth® enabled hearing systems or headphones. Since multiple devices can receive the same audio stream simultaneously, Auracast™ broadcast audio is particularly suitable for use in public spaces such as train stations, airports, museums and tourist attractions, churches, conference centres, or cinemas.

For more information, [click on this link](#).

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[WORLD NEWS – AUSTRIA – HEARRING Group – excellence dedicated to hearing implants](#)



The HEARRING 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 HEARRING clinics, their goals, and members can be found on the HEARRING website (<https://www.hearing.com/>).

HEARRING Group Quality Standards

International standards in cochlear implantation are crucial to ensure consistency, safety, and effectiveness of treatment across different regions and healthcare systems. These standards facilitate the sharing of best practices, enabling medical professionals to provide the highest quality of care. Additionally, international standards support research and innovation by providing a common framework, thus promoting collaboration and advancements in cochlear implant technology. Ultimately, these standards contribute to improved patient outcomes and a higher quality of life for individuals with hearing loss.

Therefore, the HEARRING Group has been developing quality standards since 2013, covering a series of different indications and hearing devices. The present state-of-the-art HEARRING Quality Standards are (Quality Standards – HEARRING):

- Standards of practice in the field of hearing implants
- Quality standards for cochlear implantation in adults and older adults
- Quality standards for minimal outcome measurements in adults and children
- Quality standards for cochlear implantation in infants, children, and young adults
- Quality standards for Electric and Acoustic Stimulation
- Quality standards for middle ear implantation
- Quality standards for (re)habilitation
- Quality standards for bone conduction implants
- Quality standards for adult cochlear implantation in single-sided deafness and asymmetric hearing loss
- Minimal outcome measurements in paediatric cochlear implant users: a consensus paper

They can also be downloaded as concise pocket versions with the key points summarized and the most recent literature added ([Concise Quality Standards – HEARRING](#)).

The latest HEARRING publication is a consensus paper on genetic testing in individuals with congenital hearing loss based on a survey conducted across different cochlear implant centers.

(1)

(1) Usami SI, Nishio SY, Gavilán J, et al. Testing for genetic and viral etiologies in congenital hearing loss based on a survey of cochlear implant centers: proposed HEARRING group consensus and future directions. *Acta Otolaryngol.* 2024 Nov-Dec;144(11-12):602-609

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[WORLD NEWS – POLAND – “EARPLANTED” Platform](#)



Since 2022, the "EARPLANTED" platform has supported cochlear implant users in enhancing their auditory perception and participation in social life. It assesses pitch and timbre understanding, tracks progress, and offers interactive tools such as associating melodic contours with pitch diagrams. A demo version is available (login: 555, password: 555), and we warmly welcome new users.

As part of a scientific project, we aim to develop better tools for cochlear implant users. To complete this research, we also collect data from individuals with normal hearing for comparison. Written consent ensures GDPR compliance and account registration. More details can be found on our website: <https://zaimplantowani.fizyka.uwb.edu.pl/en/>.

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WORLD NEWS – UK – AVUK – Second Year of Claire Campbell Award for Outstanding Achievement Awards – Winners announced.



(Photo: Gaea, Sanemi, Susan & Tricia)

Sanemi Parashar, Tricia Kemp and Susan Brownson have been announced as **the winners of the 2024 Claire Campbell Awards** for Outstanding Achievement.

Louis Moss and Gaea Thompson have also been honoured for their commitment to supporting deaf children achieve their potential as they are announced as Highly Commended recipients.

The awards were launched in 2023 in tribute to Claire, a mum of three, two of whom are profoundly deaf, who championed the need for early and effective support for deaf children to achieve their potential right up to her death in 2022.

Claire was a committed ambassador of Auditory Verbal UK, as its Chair of Trustees from 2013 to 2020. In memory of the dedication and compassionate support Claire gave to others - together with her family - the awards recognise the outstanding achievements of deaf children and young people and the adults who have gone above and beyond to support them.

Sanemi Parashar (12) was born profoundly deaf and had cochlear implant surgery at 15 months, followed by a reimplant less than a year later. She was supported to learn to listen and speak as a young child with Auditory Verbal therapy on Auditory Verbal UK's family programme.

Always keen to help others Sanemi promotes charity work at school where she is on the school council, is an ambassador and mentor for Advanced Bionics and supports and volunteers with hospitals, volunteer groups supporting cochlear implant users as well as with the BEARS cochlear implant trial.

On receiving her award Sanemi said: *"I am absolutely delighted to have been a finalist with some amazing young people sharing a similar journey like mine, and it feels wonderful to have won this award. I am fortunate to have all the required support and care from my family, all professionals, and AVUK who have helped me express myself with the power of speech. The award motivates me even further to continue supporting other children who are less fortunate than me."*

Susan Brownson is Deputy Headteacher and Lead of Deaf Provision at Laycock School in London, UK and is described as "a visionary leader at the heart and soul" of the provision in the capital. Her unwavering commitment to inclusion has not only transformed the lives of the children she works with but has also set a benchmark for educational institutions across the UK.

Susan said: *"I feel that this is a tribute to the many amazing children, young people and families who have taught me so much in the past forty years. The opportunities that are opening to deaf children are so much wider than when I first started teaching but we should never be complacent and should carry on ensuring that an outstanding education, with appropriate levels of support, are available to all."*

Tricia Kemp is the parent of one of the very first British children to receive a cochlear implant and set up the Cochlear Implanted Children's Support Group (CICS) in 1993 to support families and children with cochlear implants around the UK with support, advice and information.

It was and still is an independent and volunteer-led charity run by parents of deaf children. Tricia champions the achievements of children with cochlear implants inspiring others to reach their potential. Tricia said: *"I am delighted and humbled to receive this unexpected and prestigious award, especially as it is for something about which I am so passionate. It is imperative that families of deaf children are provided with support and information about how today's technology can give deaf children so much potential."*

Entries were so high this year that Highly Commended honours were also made to:

Louis Moss (12) who progressively lost his hearing and after wearing hearing aids he received cochlear implants aged seven. Louis and his family campaign to increase awareness of the need and effectiveness of early support for deaf children meeting UK MPs and conducting media interviews.

Gaea Thompson is a Teaching Assistant for the Deaf in a deaf support facility at a primary school in the UK. Gaea is deaf and has a passion to develop deaf children's identity and her award recognises the effort she goes to supporting deaf children and their families and the fun, friendly and supportive relationships she develops with the young people to help them develop language, social and emotional skills.

The awards will take place every year, so do keep an eye on [AVUK website](#) and social media for when we open for 2025 entries.

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WORLD NEWS – UK – AVUK – Young Cochlear Implant Users campaigning for increased access to early and effective support meet elected representatives in the UK – In London



(Photos: on the left, Sam outside Parliament; on the right, Graeme Downie MP with Sam, Sade & Topaz)

Deaf sisters Sade (25) and Topaz (23), Oram and Sam Callaghan (13) met UK Members of Parliament (MPs) in London in October as part of Loud Shirt Day 2024 – challenging perceptions of what deaf children can achieve with early and effective support.

They all joined Auditory Verbal UK to meet more than forty cross-party MPs, to share their stories and call on the UK Government to increase access to early, effective support for deaf children, including the support that helped them learn to listen and speak when they were young children.

AVUK's Hear Us Now campaign is calling for action to break down barriers to opportunities for deaf children and enable every family, who wants their deaf child to learn to listen and talk, to be able to access Auditory Verbal therapy through publicly funded services in the UK. Right now, less than 10% of deaf children in the UK can access Auditory Verbal therapy but there is strong support to change that.

Sam received a letter from the UK Prime Minister on the day of the event acknowledging the positive difference Auditory Verbal therapy has made to his life and how his efforts supporting the Hear Us Now campaign will help other children.

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WORLD NEWS – UK – AVUK – and young Cochlear Implant Users in Northern Ireland



Aurora (12), Noah (7), and Katie (13), who are all deaf, shared their experiences of learning to listen and talk with Auditory Verbal therapy and how they are challenging perceptions of what deaf children can achieve with the Northern Ireland Commissioner for Children and Young People, Chris Quinn, and Junior Northern Ireland Minister Pam Cameron in September.

Alongside their families, the three young people discussed with Chris and Pam what they are doing now and their ambitions for the future, following early, effective support to develop their language and communication when they were young children.

Katie is a typical 13-year-old who loves Taylor Swift and football and dreams of playing in the top collegiate USA Women's Soccer League. She wears cochlear implants and was supported to listen and speak with Auditory Verbal therapy.

Her Mum Abbie said: "Katie is the youngest of three children and by far the most confident and independent. She has always wanted to do everything on her terms and been determined that being deaf will not stop her doing anything at all. But deaf young people in Northern Ireland are still at a disadvantage to their hearing peers. This has to change."

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[WORLD NEWS – UK – The British Association of Teachers of Deaf Children and Young People \(BATOD\) Update](#)

BATOD

British Association of Teachers of Deaf Children and Young People

Revised publication (2024) – BATOD & DToD – Moving towards using positive language around Deafness/Hard of Hearing

The BATOD and DToD 'Moving towards using positive language around Deafness/Hard of Hearing' document has been updated. It is available to view via [this link](#).

Articulating the specialism (Higher education)

In November 2024, informed by past BATOD articles and experiences of current QToDs in higher education, BATOD published a new document "[Articulating the specialism – the role of the QToD in HE](#)". The QToD is known as a Special Support Professional (SSP) in HE. An SSP's input is bespoke support for the individual needs of deaf students, reflecting their method of communication, educational history, and experience.

Curriculum and Assessment Review

BATOD and NDCS submitted a [joint submission](#) response to the Department for Education (England) Curriculum and Assessment Review call for evidence.

The Specialist Deaf Curriculum Framework has been updated with new content

ALTWG publication

Hosted by BATOD, the Assistive Listening Technology working group page document has been updated with the following resource Open balancing - Ewing Foundation/ALTWG document "[Optional FP35 Open chamber FM advantage procedure](#)".

Teresa Quail

National Executive Officer and Magazine Editor British Association of Teachers of Deaf Children and Young People (BATOD)

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[WORLD NEWS - USA - ACI Alliance – Updates](#)



ACI Alliance Launches New “Ask the Audiologist” Blog

ACI Alliance launched a new blog aimed to reach individuals with hearing loss who are exploring cochlear implants for themselves, a family member or a child. Ask the Audiologist can be found on the [ACI Alliance website here](#). Questions can be submitted on the website, and we encourage people to share the blog with their networks, patients, and other audiences.

Embedding Musical Experiences in the LSL Approach

This course will cover the “why” and “how” of using musical experiences with children with hearing loss. This practical, participatory Learning Experience (LE) will support LSL practitioners and parents in utilizing music to jumpstart and expand listening, language, motor, social and emotional development. Many hands-on musical activities will be presented, along with case studies and a wealth of available resources. [Register Here](#).

Webinar: Valuing Listening for Children who are Deaf or Hard of Hearing

Hearing loss in children is now routinely detected within the first week of life, diagnosed, and referred for early intervention services by six months. Such services include provision of hearing aids, cochlear implants, or bone-anchored solutions as well as access to parent-centred habilitation to maximize spoken language and other learning. This recorded webinar will provide guidance on how to support families and professionals to value hearing and help families to pursue listening and speaking for a young child with hearing loss. [Register Here](#).

CI2024 Vancouver Selected Videos Now Available

Check out the selection of videos posted from [CI2024 Vancouver](#).

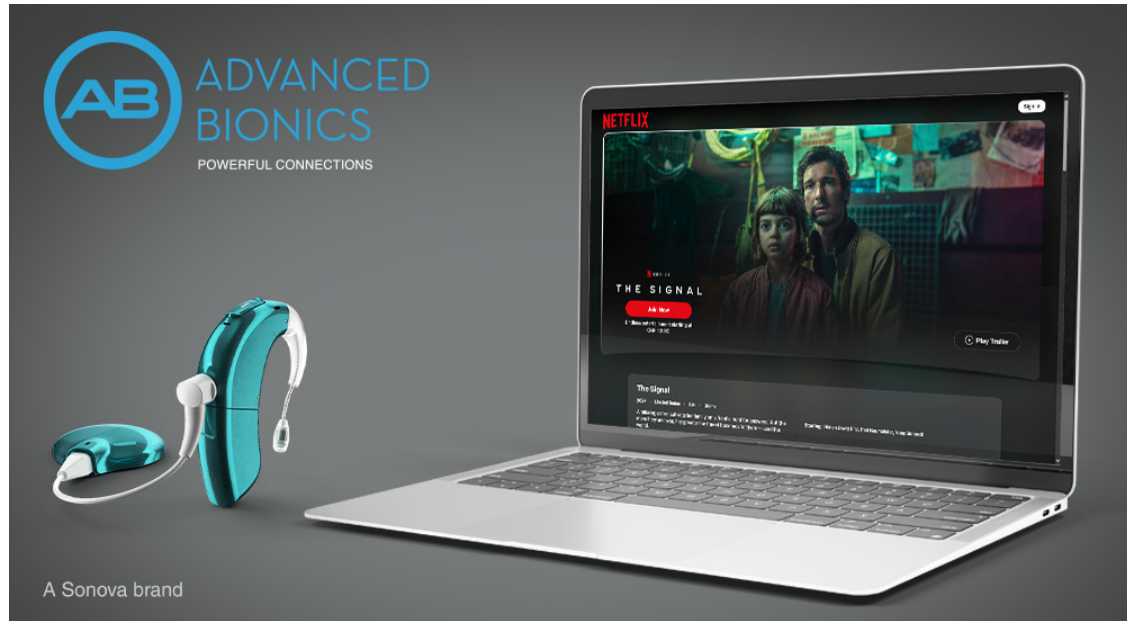
ACI Alliance Submits Formal Request for Medicare Coverage of Cochlear Implantation in Single-Sided Deafness and Asymmetric Hearing Loss

ACI Alliance submitted a formal request to the Centres for Medicare and Medicaid Services (CMS) to expand the Medicare program's coverage policy on cochlear implantation for individuals with post-linguistic sensorineural hearing loss. The organization submitted a formal Request for Reconsideration of Medicare coverage (a National Coverage Determination or NCD) based on the clinical presentation of the ear to be implanted.

Read the full [media alert](#) here.

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Advanced Bionics Featured in Netflix Series The Signal



The German Netflix thriller *The Signal* spotlights Advanced Bionics cochlear implants in its near-future storyline. This gripping drama follows astronaut Paula's mysterious disappearance after returning from the International Space Station. As her husband Sven and daughter Charlie unravel cryptic clues she left behind, they uncover secrets that could affect the entire planet.

Advanced Bionics worked closely with filmmakers to ensure an authentic portrayal, consulting CI users and families to reflect the everyday role of cochlear implants in transforming lives.

"Nowadays, the world of film is used as an opportunity to represent groups that don't appear much in society," co-creator and director Sebastian Hilger told AB. "At the same time, you also want to avoid a situation where a movie that features deaf people automatically deals with the topic of deafness. This also means that we have not achieved a commonplace. We also walk this tightrope in "The Signal", which is why we try to tell the story in a certain everyday way. We chose deafness because it corresponds well with the theme of "listening". It's a normal child to whom extraordinary things happen because it's a story. But these don't necessarily have anything to do with the fact that she is a CI user."

Featuring CIs in media helps recipients feel represented and fosters broader understanding. By featuring Advanced Bionics technology in a relatable and thrilling story, *The Signal* not only entertains but also underscores the life-changing potential of cochlear implants.

Stream *The Signal* on Netflix and see how Advanced Bionics has contributed to this inspiring portrayal!

[Watch The Signal | Netflix Official Site](#)

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Advanced Bionics – A Journey of Rebirth



Elizabeth began losing her hearing in her mid-40s and, despite advice from her hearing care professionals, delayed seeking treatment. Over the years, as her hearing loss worsened, it began to affect her family and work life. Though she consulted multiple ENTs and audiologists, the cause of her hearing loss remained unknown—a situation shared by approximately 78% of cochlear implant recipients. Initial solutions, such as hearing aids, provided some assistance but were not enough to restore her quality of life.

A pivotal moment came when a friend urged her to see yet another audiologist. This led her to a professional who not only conducted tinnitus testing but also promptly recognized her as a candidate for cochlear implants. Within five months, Elizabeth received her implant and began experiencing significant improvements, from hearing conversations without captions to sensing her surroundings more fully, such as detecting nearby cars and joggers.

Elizabeth emphasizes the value of persistence in finding the right healthcare provider and advises others to trust their instincts when something feels off. For those considering cochlear implants, her message is one of hope: while hearing may not return to what it once was, the enhanced safety, connection, and possibilities are life-changing.

Her story reminds us that with the right tools and support, life with hearing loss can be vibrant and fulfilling.

You can read Elizabeth'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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[COCHLEAR – Reflecting on 20 Years of Progress: A Farewell from Cochlear's President EMEA](#)



On the occasion of my stepping down as Cochlear's President EMEA at the end of this year, it is timely to reflect on some of the major changes I have seen in the field of auditory implants and my hopes for the future.

The last 20 years have seen significant advances in possibilities for patients with auditory implants. There have been many improvements designed from the insights of clinicians, families and, most importantly, patients. These include wireless streaming, data logging to improve user experience and the development of smaller, more powerful headworn sound processors.

Despite these advances, we have to continue towards truly empowering patients to live their full lives, and to transform the way society understands and treats hearing loss. In doing this, the importance of patient advocacy cannot be understated. Access to treatment remains difficult, with less than 5% of adults who could benefit from cochlear implantation receiving one. Yet by working together with all stakeholders, I am convinced that patient advocacy can be the driving voice for change towards better access for all.

Throughout my more than 20-year tenure with Cochlear I'm thankful to have had the privilege to interact and learn from patients. From January 1st, 2025, Anthony Bishop will take over as Cochlear's President EMEA. Currently Cochlear's President Asia Pacific & Latin America, Anthony has 30 years of experience in medical devices and I'm confident he will be a valuable patient advocacy partner.

Richard Brook,
President Cochlear EMEA

(Richard has been a huge supporter of EURO-CIU and many other not-for-profit organisations in Europe. We wish him well on his retirement from Cochlear. Editor)

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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 – 10 ways to improve your listening skills in everyday life



Did you know that you can improve your listening skills while listening to the radio, waiting for a doctor's appointment or even sitting in a noisy café?

The key, says Dianne, who uses a Cochlear™ Nucleus® Cochlear Implant System for over a decade, is to immerse yourself into activities that are part of your everyday life, and listen to the sounds around you.

Dianne shares her top 10 tips that improved her listening skills:

1. The real world is noisy. I practise listening in cafés, restaurants, at parties, and in social groups.
2. There is nothing wrong with asking politely to repeat the sentence or word.
3. Listening requires attention. You may feel at times that your progress is hindered, but it's important to continue with your effort.
4. In a group of people, I try to position myself in a well-lit area with my back to the noise, away from any music.
5. Go for a walk to hear sounds such as cars, rustling of the trees, birds, ocean waves and the sound of wind.
6. Wear your sound processor from the time you get up until you go to bedtime.
7. If you live alone, ensure you have sound around you – such as a radio, audiobooks, or TV.
8. People with an accent can be hard to understand. I make sure I'm face to face in this situation. I also give the other person my undivided attention.
9. Around the house, I had a small radio in my pocket. I didn't always know what was being said but knew I would benefit by surrounding myself with sound.
10. Don't give up.

An extensive range of resources, tools and expert advice to help navigate and enjoy the journey towards improved hearing and communication can be found on the [Cochlear website](#).

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COCHLEAR – Reconnecting with the sounds of nature



Imagine rediscovering sounds that you hadn't heard in 15 years. A feeling of excitement was what Scot had experienced when he started to hear the sounds of nature that he'd been missing for so long.

"We were coming down the road and there's a wetland area down there. And Chris makes me stop and we roll down the windows and there's frogs," says Scot. "It was crazy what I was hearing. I couldn't hear enough of it ... it puts a smile on your face again."

Now with his Cochlear™ Nucleus® 8 Sound Processor, he's looking forward to more adventures with his wife, Chris, and his two adult daughters.

"It's gonna be fun growing old now and being able to hear again," says Scot. "The technology, you can't believe what is offered here, and what you can have."

"Before I got my cochlear implant, I didn't like the aesthetics part of it. What are people gonna see? What are people going to think?" says Scot. "Now I'm kind of proud about it and I show it off. It's comfortable. I don't realise that it's even there at all. The fit is just incredible."

As a relatively new recipient, Scot is noticing how much progress he is making with his hearing. *"My daughters, they're happy and can see a difference in me. It's just so much nicer around the kitchen table or just hanging out with them now," says Scot. "I'm excited for, you know, how am I gonna hear next week? I'm excited, you know, to go now and be with people. I'm excited for Chris and I to go on an adventure."*

To find out more about the benefits of upgrading to the Nucleus 8 Sound Processor, visit the [Cochlear website](#).

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MED-EL – Healthy Hearing for Healthy Ageing: A Webinar by the European Commission

LIVE WEBINAR

“Healthy Hearing for Healthy Ageing - Addressing Challenges of Hearing Loss in the EU”

hosted by European Commission & Hearing Health Forum EU



HEARING HEALTH
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hearing

On 5 December, the Hearing Health Forum EU partnered with DG SANTE of the European Commission to host a pivotal live webinar. The event spotlighted the challenges of hearing loss, a condition affecting 34.4 million Europeans, and its profound impact on ageing populations.

The webinar Healthy Hearing for Healthy Ageing addressed the hidden epidemic of hearing loss, its social, economic, and health repercussions—including cognitive decline, social isolation, and diminished workforce participation—and the pressing need for action. Despite its prevalence, hearing loss remains often underdiagnosed and overlooked.

During the session, the Hearing Health Forum EU presented its [Policy Manifesto on Hearing Health](#) and outlined concrete policy recommendations for improving hearing care across the EU. These included recognizing the widespread impact of hearing loss, integrating hearing health into national policies, advancing research, and ensuring equitable access to screening and treatment. Participants were encouraged to endorse the Hearing Manifesto, urging policymakers to prioritize hearing health and improve standards of care, ultimately enhancing the quality of life for millions of ageing Europeans.

Your Signature Matters

EURO-CIU fully supports the Policy Manifesto and asks you to join the movement to advance hearing health in Europe. Endorse the Manifesto today and advocate for a European Hearing Health Strategy: <https://www.hearinghealth.eu/hearing-loss-manifesto/>

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MED-EL – Young Geniuses Wanted: Enter the IDEASforEARS Contest!



It's that time of year again! On November 9, MED-EL launched the next edition of the IDEASforEARS contest, which invites children between the ages of 6 and 12 years to spark their creativity and come up with amazing ideas that can help people with hearing loss and/or hearing implants.

Does your child have a brilliant idea that could make life easier for those with cochlear and other hearing implants? It could be anything from a cool gadget to a clever improvement of the CI or an imaginative solution to a common hearing challenge.

IDEASforEARS benefits

Apart from the joy of sharing your ground-breaking ideas, there is the chance to win a fabulous trip to Innsbruck, Austria, where MED-EL is headquartered!

Here's what awaits the lucky winners:

- **Global Friendships:** Winners will meet other young inventors from around the globe, share experiences, and make new friends.
- **Meet the Makers:** Winners will get the unique chance to talk to the people who made their or their family member's cochlear implants. They will also meet real inventors from MED-EL's Research & Development department.
- **Explore the Facilities:** Winners will see how and where cochlear implants are made at MED-EL headquarters.

- **Interactive Learning:** Winners will visit Audioversum, a unique interactive hearing science museum, where learning about hearing is real fun.

The deadline for submitting ideas is 17 January 2025.

Encourage your children to grab their pens, markers, and thinking caps, and start brainstorming! Let's make a big difference together and help improve the world for cochlear implant users with your creativity.

For impressions from last year's winner event and more details on how to enter, [visit our IDEASforEARS website](#).

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[MED-EL – Be Flexible. Be Free.](#)



Introducing SONNET 3, the latest behind-the-ear cochlear implant audio processor from MED-EL.

It has a smaller and lighter waterproof * design and a flexible earhook you can bend to comfortably fit your ear, keeping SONNET 3 securely in place.

SONNET 3's time-saving touch key can be programmed to either switch between programs or activate standby mode with ease.

And thanks to integrated direct streaming, you won't need any additional devices to connect SONNET 3 to smartphones, tablets, and smart TVs.

Experience your best hearing in any environment and hear the details of music and speech thanks to closest to natural hearing with SONNET 3. Find out more about this great option for both new and upgrade users: <https://www.medel.com/hearing-solutions/cochlear-implants/sonnet3>

** IP68 rating: Waterproof for immersion in water up to a maximum depth of 1 meter for 60 minutes. WaterWear is recommended for swimming and showering.*

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