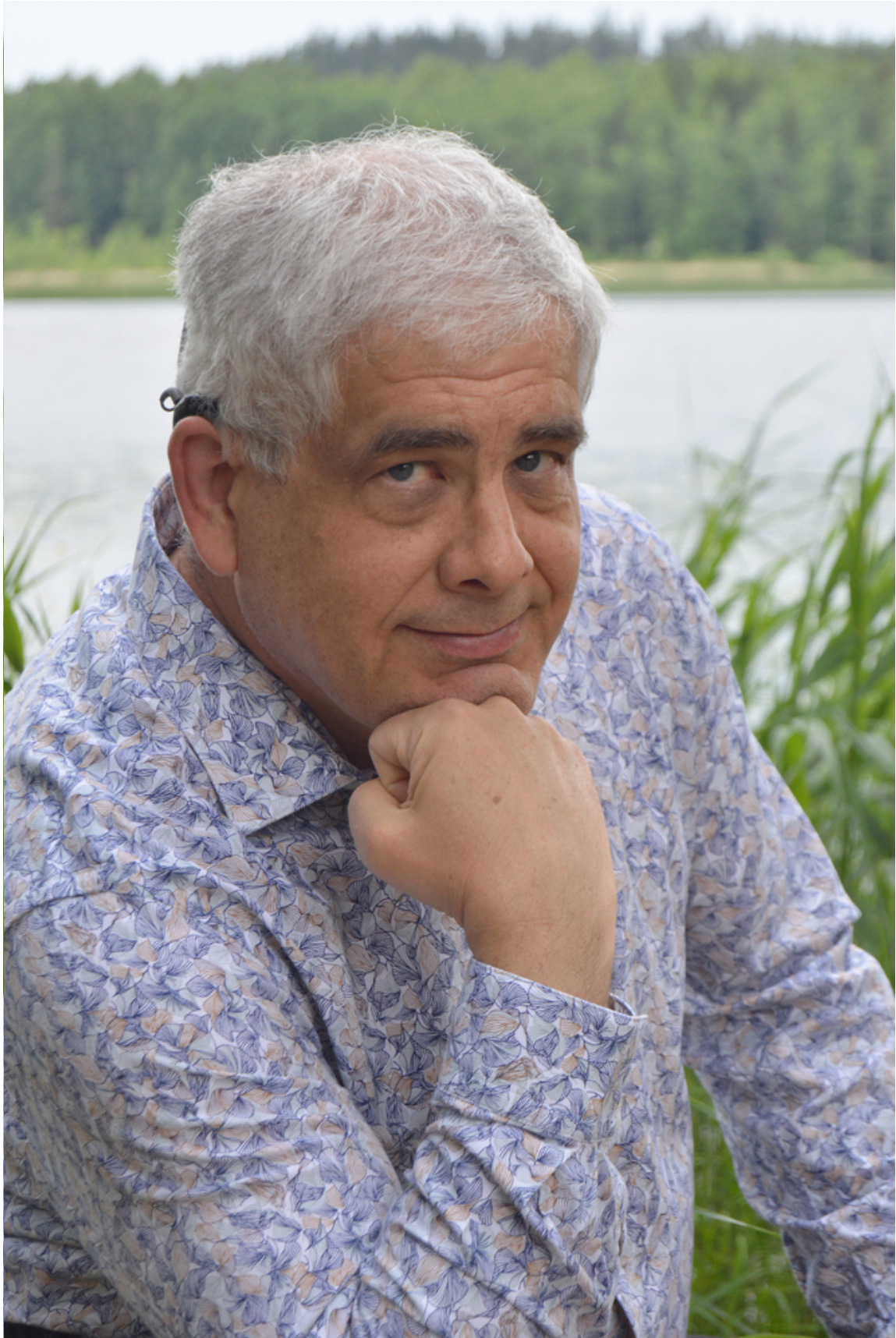


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Message from the First Vice President



As Joan Zamora is in hospital, Teresa has asked me to write a message for this newsletter. We are obviously thinking of Joan and his family at this time.

I must draw your attention to two very important topics:

EURO-CIU Symposium and General Assembly: You will see the article below that Hennie Epping, Peter Helmhout, Henk van Rees & Leo De Raeve have written about the forthcoming EURO-CIU Symposium and General Assembly, which we would encourage you to attend. We hope that you will register, if you haven't already done so, and we look forward to seeing you in Rotterdam. It will be so good to be able to meet up face-to-face again.

Could YOU be the next EURO-CIU secretary? We will elect a new Secretary for EURO-CIU at the General Assembly to join our small team looking after the interests of EURO-CIU. To apply, you must be a member of one of EURO-CIU's member associations for your country, and your application must be supported by your home association. We anticipate that the successful candidate will serve a three-year term to 2025. As Secretary, you have the opportunity to gain an international perspective, advocate for cochlear implants and help to steer EURO-CIU along its path. The job description and application form are available from our Second Vice President, Beatrice Cusmai, and you can e-mail her at beatrice.cusmai@aguav.it. All EURO-CIU board members are voluntary and unpaid. Your duties would include taking meeting minutes, co-operating with host countries of our events, maintaining member databases, and developing our internal/external communications. The line-up of the board will be significantly refreshed next year, so this promises to be an exciting and rewarding time for the new Secretary who will provide continuity between this board and the next. Applications should be returned to Beatrice by Monday 31 October. If you would like any further information, please contact either me at robert.mandara@elisabet.fi or Beatrice.

I hope that you have had an enjoyable summer, and I look forward to seeing many of you in Rotterdam.

Robert Mandara
First Vice President

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[Message from the Newsletter Editor](#)



Many thanks for all your contributions - it's good to hear from you all. It's reassuring that activities have started again, after the last three years of Covid restrictions. And 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!

The next edition will be due in December (where has the year gone?!), so please let me have your articles and jpg photos by Monday 5 December 2022. Just e-mail them to me at newsletter@eurociu.eu

It just leaves me to wish you good health.

Brian Archbold (Editor)

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[EURO-CIU – Register now for the XIII EURO-CIU Congress in Rotterdam](#)



In previous newsletters we have advertised the XIII EURO-CIU Symposium, “CI what do we already know and what can we expect?”, organised in cooperation with ONICI and OPCI.

IMPORTANT! EURO-CIU members are strongly urged to **register as soon as possible**, to ensure entry to this great event. Demand from non-members is already high, which is great, but this creates a high risk that late EURO-CIU member registrations would have to be turned away. Capacity of the venue is strictly limited.

The Symposium (11th November) and General Assembly (12th November) will take place in the middle of the vibrant and beautiful city of Rotterdam (link to program). Preparations are at an advanced stage and the organizers are just putting the finishing touches to the program.

We look forward to welcoming and meeting as many EURO-CIU members as possible at the congress, as well as other interested parties and visitors. To ensure your participation, **don't delay, register today!** The closing date for registration as a member of EURO-CIU as well as for booking a room in the conference center is October 15.

In the unlikely event that your member association has not received the registration invitation email, please contact: registration.eurociucongress22@onici.be

***Hennie Epping, Peter Helmhout, Henk van Rees & Leo De Raeve**
the EURO-CIU 2022 steering group, a joint initiative of OPCI and ONICI*

CONFERENCE PROGRAMME

Thursday 10 November 2022

18.00-19.30H Opening reception (only for EURO-CIU members)

EURO-CIU members attending the 13th EURO-CIU symposium are welcome at the opening reception.

Friday 11 November 2022

8.30-9.00h **Registration & coffee**

9.00-9.10h Hennie Epping, OPCI (NL) Welcome + introduction
9.10-9.22h Teresa Amat, EURO-CIU (ESP) 25 years Euro-CIU
9.22-9.35h Representative Rotterdam Welcome by the city of Rotterdam
9.35-9.55h Mark Laureyns, WHO (B) How can we leverage the World Report on Hearing (WHO) to minimize the impact of untreated hearing loss?
9.55-10.15h Prof. Johan Frijns, LUMC, Leiden (NL) Cochlear Implants in the future: what can we expect?
10.15-10.35h Robert Mandara, EURO-CIU (FI) The importance of CI advocacy
10.35-11.05h **Coffee break & Exhibition**
11.05-11.25h Presenter OPCI (NL) Adult cochlear implant advocacy in the Netherlands
11.25-11.45h Anita Grover, AV (UK) Habilitation after CI
11.45-12.05h Harald Seidler, ZAB Neunkirchen (D) Good practice in rehab after CI in adults
12.05-12.25h Katrien Timmerman, KIDS, Hasselt (B) Output without input?
12.25-13.35h **Lunch & Exhibition**
13.35-13.55h André Goedegebure, Erasmus MC, Rotterdam (NL) Impact of CI on the brain in adults & children
13.55-14.15h Enrico Migliorini (It), MOSAICS project Unravelling speech errors may lead to improved speech understanding
14.15-14.35h Aimée van Loo, University College Zuyd, Heerlen (NL) What to do in rehabilitation after cochlear implant?
14.35-15.05h **Coffee break & Exhibition**
15.05-15.25h Prof. Astrid van Wieringen, KULeuven (B) CI in children with single-sided deafness: longitudinal data of language and hearing
15.25-15.45h Brian Lamb, CIICA (UK) What does a CI costs ?
15.45-16.05h Leo De Raeve, ONICI (B) Closing Session
16.05-16.25h David Aris (NL) DJ with two CIs

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[EURO-CIU – Optimising care through Living Guidelines](#)



COCHLEAR IMPLANTATION IN ADULTS

OPTIMISING CARE THROUGH LIVING GUIDELINES

Cochlear implants (CIs) are an effective medical treatment for many adults living with severe, profound, or moderate sloping to profound sensorineural hearing loss (SPSNHL). However, it is estimated that only ~5% of adults who could benefit from a CI have one.^{1,2}

An international collaboration of hearing experts, known as the CI Task Force, are leading the effort to develop Living Guidelines that will optimise care for hearing impaired adults, improve CI accessibility, and standardise treatment globally.

In the previous EURO-CIU newsletters, I informed you about the Living Guidelines initiative, which is an essential step to addressing significant unmet need and improving outcomes for adults with a hearing loss around the world. Local CI User advocacy organisations and international organisations like EURO-CIU and CIICA will play an important role to disseminating information about the guidelines and to ensure that consumers are empowered with knowledge about CI as a treatment option for them.

HT Analytics, the Australian group employed to manage the Living Guidelines project, works closely together with the 3 co-chairs of the Task Force (Dr Angel Ramos, Meredith Holcomb, Leo De Raeve), a Task Force of more than 50 hearing experts from around the globe and CIICA.

At this stage HT Analytics has reviewed approx. 14,000 publications and has interviewed the

Task Force members. A new briefing on the Living Guidelines was published in July 2022: <https://adultheating.com/living-guidelines/>.

CIICA has also organised a CIICA conversation held on 7 July 2022. It gave an opportunity for Adult CI users and family members to discuss the Living Guidelines initiative and to put the user perspective to the issues being explored. 21 CI-users and family members, with 3 professionals had a lively discussion on the project, sharing the issues important to them. The summary of this event is downloadable from the website of CIICA: <https://ciicanet.org/events/ciica-conversation-adults-with-ci-talking-about-the-living-guidelines/>.

The next step is to create global living practice guidelines and guidance that can be adapted and adopted in each country, to optimise the standard of care for adults eligible for CI. Additional implementation activities will be undertaken based on regional and country-specific requirements.

Everyone in the broader hearing community has a role to play to share this information and increase awareness of the Living Guidelines project and the need to improve access to optimal hearing care. For more information about the Living Guidelines Initiative and the Task Force please visit : <https://adultheating.com/living-guidelines/> or contact me at leo.de.raeve@onici.be.

Dr Leo De Raeve
EURO-CIU Scientific Advisor

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CIICA Conversation: Experiences of tinnitus and CI

CIICA CONVERSATION: EXPERIENCES OF TINNITUS AND CI

WED 14 SEP 2022 19.00 UK; 20:00 CET; 14:00 EST; 11:00 PST. THUR 15 SEP, 04.00 AEDT



Robert Mandara



Julianna Franchetti

Although most forms of ear and hearing problems can be effectively managed with modern technology, tinnitus remains an invisible unaddressed burden to many.

In this CIICA conversation, led by Robert Mandara (Vice-President, EURO-CIU) and Julianna Franchetti, both CI users, we would like to hear and discuss your thoughts and experiences on all aspects of tinnitus in relation to CI. For example:

- Do cochlear implants improve or worsen tinnitus? What concrete or anecdotal evidence is there? What are your experiences?
- What do CI users find helps or worsens their tinnitus?
- Are clinics asking about and taking tinnitus seriously?

Please register and join this conversation if you are, for example, a tinnitus sufferer, CI user, a parent of a CI user, or a professional working in the CI and/or tinnitus field.

Places are strictly limited, with no space for spectators! Our CIICA Conversations have small groups and last one hour. Live captioning will be provided in English and other languages by request.

Register at www.ciicanet.org and have your say!

On 14th September, 20:00 (CET), CI users Julianna Franchetti and Robert Mandara (EURO-CIU Vice-President), will lead a 60-minute CIICA conversation on the important topic of “Experiences of tinnitus and CI”.

In a small friendly group, we will discuss topics including how cochlear implants affect tinnitus, how we manage our tinnitus, and how our CI clinics approach our complaints about tinnitus.

Anyone can register and places are strictly limited. This is a particularly good opportunity for CI users who have tinnitus, or used to have it, to participate and share their experiences.

The conversation will be in English with English subtitles. Additional subtitle languages can be requested upon registering.

Please see the official invitation and registration details at: <http://ciicanet.org/events/>

EURO-CIU is a founding member of CIICA

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CIICA LIVE: Young people with CI, our opportunities and challenges



Wednesday 28 September, 20:00 UK time, 21:00 CET

Chaired by Bowen Tang, CI User, and President of the International Federation of Hard of Hearing Young People, IFHOHYP and with young CI users, families and those providing services around the globe will contribute.

Young CI users will share their experiences about the challenges and opportunities at home, school, higher education and work. We can all learn from what the young people tell us: as Bowen recently commented: "We don't know what we don't know... our technology has to last us a lifetime... we need to take ownership of it".

What can we learn and provide for their future services to ensure lifelong provision and maximise the benefits of CI for this new group of young people?

See the exciting programme and join us, whatever your age!

- **Welcome and Young People with CI: Bowen Tang**
- **Listening to Young People in School: Maricris Ibayan**
- **Educating the Educators: Jana Beneito**
- **Using the Power of Cognitive Neuroscience for CI users: Helen Willis**
- **Dealing with the workplace : and the boss! Qais Khan**
- **CI services for young people: more than just sound and devices: John Lui**
- **Future Technologies for CI Users: Daniyaal Munir**

Register in advance for this meeting:

<https://us02web.zoom.us/meeting/register/tZMtCuiprTMqEtMb8APM9oqMKJQFGYIrBdDn>

EURO-CIU is a founding member of CIICA

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AUSTRIA – Cochlea Implantat Austria (CIA) – Summer Days 2022 – a record

year!



The CIA Summer Days took place for the 18th time this summer; and already the third time being organized by the next generation – Max Breyneck, the 30-year-old CI-user and participant from the very beginning, took over the project from his mother Birgitt Valenta in 2020.

This organizational renewal and the fresh approach is paying off: in 2022 more families than ever before took part. With 150 participants, including 25 very young children under the age of four, this year was a record year!

Some of the families have been participants since the start, their children are now adults – and are still looking forward to the yearly reunion. They are now essential conversation partners for the many new CI-children and their parents. Getting to know each other and the exchange with fellow parents gives them a lot of strength and confidence for the road ahead with their children.

In addition to an active and entertaining programme, experts from the 'hearing' and 'CI' field are available for discussions. Most important though is the exchange of experiences and the sense of belonging together. The common history and road back to 'hearing' forms a strong bond, which especially felt strong when there. Whether in discussions, leisure activities or during the creative workshops – being part of this special group gives parents and children strength, from which they can draw for a long time, even when the Velden days together are long gone. Therefore, organizer and CI-user Max hopes that many more new CI families in Austria will join, that they too can experience this very special time in Velden am Wörthersee.

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[AUSTRIA – Cochlea Implantat Austria \(CIA\) – Successful Singing Workshop](#)



A singing workshop was organized in Lower Austria for hearing implant users. Its main focus was to enjoy what we were doing rather than singing in perfect pitch.

Two experienced conductors led the workshop: Johanna Boyer, musicologist and single-sided deaf CI user; and Bianca Wirthner, music therapist at the ENT clinic in St Poelten, Lower Austria, who works extensively with CI users.

Fifteen singers from Austria, Germany, Switzerland and South Tyrol participated in two groups, beginners and advanced level. They trained their hearing by listening to each other, finding the right pitch, staying in the rhythm and keeping the tempo. All these tasks are also beneficial for speech understanding in noise and enhanced music enjoyment.

Breathing and dancing

Breathing techniques are important when it comes to singing, so the two conductors dedicated a lot of time for breathing and warm-up.

In the course of two days, the participants learned five songs from different genres – and with a lot of fun. “Singing in a group is totally different from singing alone with my piano”, commented Laura, a bilateral CI user and music teacher.

The singers thoroughly enjoyed the various rhythm games, songs that were accompanied by movement and clapping and a special folklore dance evening. “Dancing was great to get to know the other participants,” was the feedback from the group.

The CI users, from their mid-twenties to early eighties, also loved the opportunities to share experiences.

Fun and success

Although the focus of the singing workshop was put on enjoying music together, every single person was highly committed and engaged. Progress was clearly audible between the first and the last day. The group had developed into a harmonic choir. Results were presented at the end of the workshop, when some of the participants performed their favourite song. Harold, who on day one of the workshop had been shy to sing, sang an entertaining duet, accompanied by accordion. His conclusion: “In the beginning I was afraid to sing, but now I am enjoying it!”

With the Ode to Joy, the singing workshop ended on an emotional and joyful note.

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AUSTRIA – Cochlea Implantat Austria (CIA) – CIA in Lower Austria active again



The restrictions because of the COVID-19 pandemic caused a break also for the meetings of self-help groups. This summer the group in Lower Austria recovered their activities.

"You haven't changed at all!" Chairwoman Gertrude Moser greeted her guests. The corona pandemic had made club meetings difficult or impossible for a long time. Finally, on May 27th, 2022, the members of CIA Lower Austria met again at a wine tavern in Kasten in Lower Austria. 30 participants enjoyed good dialogues, good food and wine and exceptionally good weather. Heinz Kirchschrager, CI-user, member of CIA and passionate musician, also played on his accordion.

Even more participants attended the summer-party at the inn "Gnasmüller" in Totzenbach, already a traditional place for parties of CIA Lower Austria. Within the participants were founding members – the group exists for 18 years now – as well as new guests and CI-candidates. It became an afternoon of excellent conversations, since many of the participants know each other for such a long time, yet.

Delegates from CIA Austria, CIA chairmen Hans Horak from Vienna and Karl-Heinz Fuchs from Upper Austria, attended the events.

Photo ©Emmerich Moser

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POLAND – Stowarzyszenie Słyszeć bez granic (SSBG)



Dear Newsletter readers

As you know, the beginning of the year did not turn out to be a happy one for everyone. First the pandemic, which spoiled plans in our activities and meetings, then the war in Ukraine.

Our Association took on the task of helping to fundraise for implant batteries and hearing aids. Thanks to the collection at <https://www.siepomaga.pl/sluch-dla-ukrainy>, we were able to purchase and support deaf and hard of hearing people in war-stricken Ukraine. Thanks to the support of people in our European community, we also received batteries, which were also sent to those in need. All information is included in the collection link. We encourage you to take a look there and ask for further financial support to send the batteries that have been collected.

In addition to the Ukraine-related activities, we organised two eco-fests. One was held in Chojnice and the other in Bydgoszcz. The festivals were intended to make children more aware of hearing and to show its connection with ecology.

As an association, we are continuing the "Save the world and hearing with bottle tops" campaign. As you know, this is about the National Hearing Aid Bank SSBG and the home rehabilitation of children with hearing impairment. Finance is needed to work towards this goal. The collection of bottle tops and then raising money from sales allow us to continue these projects. As an association, we have also been granted the status of a public benefit organisation. We encourage you to follow our activities on our website and invite you to a photo report:

Festival in Bydgoszcz:

<https://www.facebook.com/slyszecbezgranic/posts/pfbid0BxcZvMvVGWltMGQcKn9B5thNFcBULA2YkRec8WoHiuUCEiXxC89edoEf35fws2eEI>

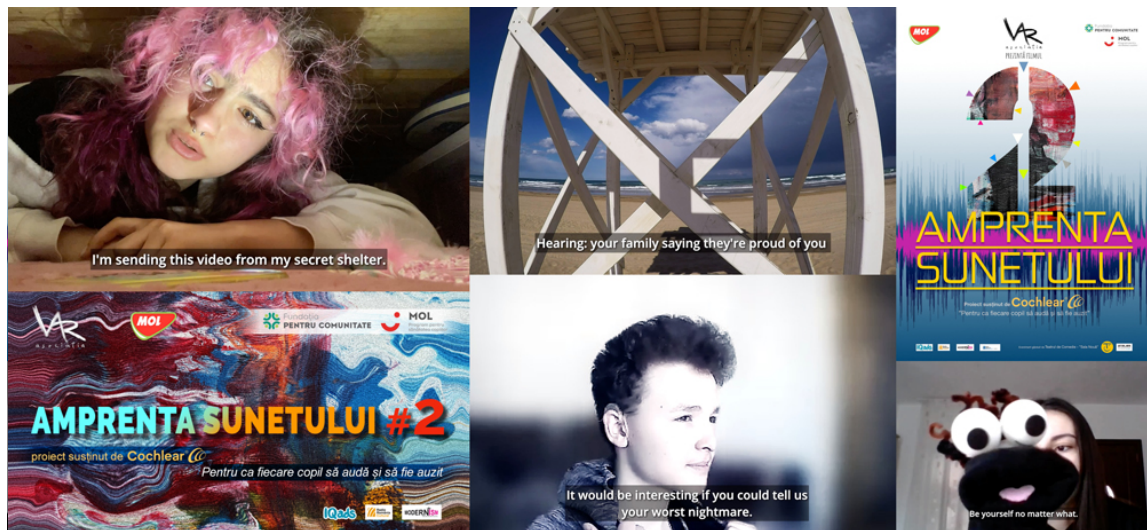
Festivities in Chojnice:

<https://www.facebook.com/slyszecbezgranic/posts/pfbid0PWWU3XU3tae7KFjsBX2Um2kNS2EQRT1T9qVg9rwDwdAnP1rTWk6R1gnu1uP8SWwul>

Żaneta Miecznikowska

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[ROMANIA – Ascultă Viața – Sound Imprint 2](#)



SOUND IMPRINT 2 – the second medium-length film produced by the **VAR Association** – is a production that reflects the quintessence of a project dedicated to hearing-impaired teenagers and preteens (cochlear implants/hearing aids users) from Romania.

For 10 weeks (January- March 2022) 16 young people, gathered from different regions of the country, were challenged through online workshops based on play therapy techniques, percussion, puppet making and visual arts (film, drawing and photography) to discover and value their inner resources, generating their own visions and creations.

During the two months, guided by the project implementation team, they managed to create over 400 video and audio materials which went through a careful selection process in the post-production stage. Therefore, the images and sounds found in the film highlight their identity, resources, quests and wishes. Through this film, the initiators aim to promote diversity and tolerance, thus increasing these youngsters' degree of awareness and acceptance of reality. The audience have the opportunity to discover unique visions and approaches – realities seen, heard and felt by them. An honest dialogue between the creators and the wide audience.

You can watch it here: <https://www.varcultural.eu/amprenta-sunetului-2-en/>

The team: Vero Nica: documentation/script/project coordinator / Magda Cernea: coordinator / workshop instructor / Andu Dumitrescu: director/ sound designer/ editor / Nicoleta Codorean (Marriolle) – puppeteer / puppet workshop coordinator / Alex Neagu – musician/percussion workshop coordinator

SoundImprint II is supported by Cochlear. Helping Children "Hear now. And always."

Project supported by the Community Foundation and MOL Romania through MOL Child Healing Programme

A film by: Natalia Almași / Anisia Banculea / Elena Bușu / Ioan Nectarie Kristensen Chelcea / Nicolae Teodor Kristensen Chelcea / Andrei Drăghici / Liviu Enescu / Nicola Ghinea / Constantin Nectarie Gora "Costea" / Sonia Mihăilescu / Șerban Mina / Alexandru Mocanu / Matei Mortu / Luana Popa / Albert Sivriu / Cătălina Vasile

Partner organization: "Ascultă viața", "Audiosofia", "Koala RAV", "Perspective pentru Copiii Hipoacuzici", "Auzi Înțelegi Trăiești", "Darul Sunetului", "Să auzim glasul mamei"

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SWEDEN – Barnplantorna Summer Camp, a tradition since 1997



Photos from the Summer Camp

Since 1997 Barnplantorna has arranged a summer camp every second year. The camp has offered unique possibilities for deaf children, hearing with cochlear implant or other hearing solutions. It has also been important for siblings. During a week, parents have been updated with knowledge, not always available in Sweden due to a strong deaf culture.

In the early days (1990s) most children with CI were signing and very slowly developed some spoken language. Over the years, communication between the children has followed the following development pattern:

- Early CI assessment
- Newborn hearing screening – CI surgery at the age of 5-6 months
- Bilateral implantation

Now many of the children have a normal spoken language development.

Parents have for years (during the summer camp week) been updated with knowledge about possibilities for their children and to have high expectations concerning hearing and spoken language development for their children. During this time, Barnplantorna has also provided parents with knowledge about their role in their child's development. A lot of world-famous experts within this field of hearing loss in children and cochlear implants have over the years attended Barnplantorna summer camp in Helsingborg by the southwest coast of Sweden. Speakers such as Amy McConkey Robbins, Amy Birath, Pamela Talbot, Carol Flexer, Suzanne Harrigan, Sue Archbold, Diana Harbor, Christine Rocca, Clare Allen, Jon Shallop etc.

This year's summer camp was postponed because of the Pandemic from 2021 to July 2022. Many parents have been longing for attending the camp, to meet others as well as be updated with knowledge. One comment that we unfortunately still meet among parents is:

"Why haven't we received this information from the family intervention team where we live?"

This year Amy McConkey Robbins made huge impact in talking about "work smarter, not harder" and "building a strong language foundation in children with hearing loss".

Ulrika Löfkvist PhD (Uppsala University) talked about family intervention as well as PEPP (Parent Education Preparation Program). Other Swedish speakers that contributed were MD Radi Jönsson ENT clinic Sahlgrenska university hospital (SU) Gothenburg as well as Jan Andersén psychologist SU Gothenburg.

After many activities during five days, Friday came. Everyone was, for sure, tired – parents filled with knowledge and ready to continue their role in working for the best of their children and the children – they all had lots of fun.

Barnplantorna summer camp was another success, showing that the possibilities for deaf children never have been greater. Who could imagine that in the beginning of 1990?

Program (in Swedish) [Program_Barnplantorna_Sundsgarden_2022_2.pdf](#)

Ann-Charlotte Gyllenram
BARNPLANTORNA

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[UK – The Cochlear Implanted Children's Support Group \(CICS\) – London 10k Run](#)



The Cochlear Implanted Children's Support Group (CICS) is a national voluntary independent support group for families in the UK whose children use cochlear implants and for those who are considering cochlear implants. Run by parents, the charity provides information, contacts, events and support. Membership is free and the charity relies on donations to cover costs and subsidise events.

On one of the hottest days of the year (and that is saying quite something for 2022 where we have seen record-breaking temperatures in the UK!) 20 determined and enthusiastic runners put on their CICS running shirts and took to the streets of London for the ASICS London 10k Run to raise money for CICS.

It was wonderful to have two young adult CI users in our team, Sam Dunstan who has run in several such events for us, and Owen Fan taking part for the first time with his father Pete. Mums, Dads and family friends made up the rest of the team and we were delighted and relieved that they all completed the challenge in spite of the tremendous heat, and we are extremely grateful to each of them and their supporters for raising money for the CICS Group.

It wasn't just the runners who were out in the heat. We had a tremendous supporting team of cheering flag-wavers at various points along the route. The distinctive colours of the CICS running team shirts helped supporters to spot team members in the mass of runners as they went past. Family members, friends and supporters of the charity shouted encouraging messages to help lift the runners' spirits as they pounded the streets.

At the end of the run, everyone met up at a private function room at Browns Restaurant in Covent Garden where light refreshments were provided for runners and their supporters, but first stop for some of the team was a separate room where two fantastic volunteers, CI user Rebecca Zelic, a recently qualified physiotherapist, and Nirmala a sports massage therapist, helped to ease their aching muscles.

The charity's Coordinator, Tricia Kemp, made a short speech thanking runners, supporters and volunteers, and a celebratory cake was ceremoniously cut by CI sisters, Jessica aged 11 and Penny aged 8, whose Dad, Oli was a runner in the team.

Of course, the initial reason for CICS taking part in this event was to raise money, but offering a post event get-together at Browns made it about so much more than that, and demonstrates the true spirit of CICS. It brought our runners, their families and supporters together to share the full experience of the event. The younger CI children met some older ones, parents made new contacts, and friends and relatives gained a better appreciation of the value of the supportive network that CICS can provide.

As the charity's only major fundraising event each year, the London 10k is very important to us, and we are really grateful to our 2022 10k team for taking part, and to their sponsors for their generous support.

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[WORLD NEWS – EHIMA – the European Medical Device Regulation \(MDR\) Update](#)

After a few years of calm, the troubled implementation of the European Medical Device Regulation (MDR) is re-erupting as a dominant item on the health agenda in Brussels.

Policy and civil society stakeholders across the healthcare spectrum have long warned about the mismatch between the industry's re-certification needs and the resources available to this end (particularly Notified Body capacity and Medical Device Coordination Group (MDCG) guidance). But with only two years until the end of the transition period and still no systemic solution in sight, the debate is now increasingly taken into the open.

Following the June health ministers' meeting and its critique of the European Commission, and the Commission's own "blame notice" implicating the industry, other actors are now forcefully rebuking the Commission's claims: A MedTech Europe survey about the barriers encountered by the industry delivered a scathing verdict: Calling out the MDCG itself as a cause of crisis, due to late and unclear guidance documents, which has allowed only 15% of devices to achieve re-

certification to date, and with companies planning to reduce their product portfolio by an average 20%, indicating a substantial loss of devices.

Stakeholders are now scrambling for corrective solutions – The trade organisation, COCIR, approached the Commission with a menu of possible options, including a certification waiver for low-risk devices; and a group of 35 MEPs around Germany's Angelika Niebler called on the Commission to outright abort the 2024 deadline and extend the transition period for an undefined period of time.

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WORLD NEWS – The International Federation of the Hard of Hearing Young People (IFHOHYP)



I had an opportunity to attend the study session “Advocating for our rights through leadership”,

organised by the International Federation of the Hard of Hearing Young People (IFHOHYP) with the Youth Department of the Council of Europe. The study session took place in the European Youth Centre Budapest from 22nd to 27th August 2022 and aimed at empowering hard of hearing young people in effective leadership in organisation, advocacy work and developing a more inclusive world by bringing positive attention to disabilities and the human rights movement.

This has been the most unforgettable, life-changing experience of my life. 30 young adults who are hard of hearing from around the world met together in one big room to be empowered, improving competence skills such as how to build leadership, improving our public speaking skills, turning our ideas into reality through project management, and actions that can be used in the fight for the human rights of deaf/hard of hearing people.

The whole six days were full of creativity, innovative ideas and working together as a team. The study session has helped me improve as a leader and an overall individual in numerous ways. This allowed me to assess my strengths and weaknesses, and has forced me to outline my goals as an individual, which helps me in achieving them. They have also taught me to take action when possible. It helps young adults who are hard of hearing to get up in front of the class each and every day to present, to share our passions and ideas, to conduct reviews, and that has helped us tremendously. This allowed us to gain experience and confidence in front of a large group of peers. It was a good opportunity to learn from practice, reflection, and observation during all this time.

This course was perfect for hard of hearing young people who struggle to work as a team, to speak front of a crowd and hope to improve their leadership skills. We all had a wonderful time, and huge thanks to everyone who made it possible!

Qais Khan

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WORLD NEWS – World Hearing Day 2023



Ear and hearing care for all! Let's make it a reality

The next World Hearing Day will be observed on 3 March 2023 with the above theme:

Through this theme, WHO will highlight the importance of integrating ear and hearing care within primary care, as an essential component of universal health coverage.

The key messages for WHD 2023 are:

1. **Ear and hearing problems are among the most common** problems encountered in the community.
2. Over **60%** of these can be identified and addressed at the primary level of care.
3. Integration of ear and hearing care into **primary care services** is possible through training and capacity building at this level.
4. Such integration will benefit people and help countries move towards the goal of **universal health coverage**.

The WHD 2023 will mark the launch of:

The Primary ear and hearing care training manual for health workers and doctors. The manual will be accompanied with trainer's handbook and other community resources.

More information on the campaign is available on the [WHO website](#). For those who wish to adapt these visuals to suit their own campaigns, edit-able formats are available upon request by writing to whf@who.int

We hope that the World Hearing Day 2023 will be a massive call to action. All sectors can demonstrate their leadership by making this year's event the largest one the world has ever seen.

Thank you for your support.

Best regards,

WHO Ear and Hearing Care Programme

[#WorldHearingDay](#) [#HearingCare](#)

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[WORLD NEWS – Usher News & Highlights 2022](#)



Author: Dominique Sturz, Patient Advocate Usher Syndrome & Rare Diseases, ePAG ERN-Eye (European Patient Advocacy Group European Reference Network for Rare Eye Diseases), Usher Contact CIA (Cochlea Implantat Austria); Usher Initiative Austria

International events relevant for people living with Usher syndrome:

Why are they relevant for the CI community?

Usher Syndrome is the most common cause of combined vision and hearing loss and deaf-blindness, and is characterized by congenital (sensoneural) deafness or moderate progressive hearing loss and by vision loss starting in early childhood or teenage years depending on subtype and underlying genetic cause.

ERN-Eye General Annual Meeting 25-26 April 2022, Amsterdam

European Reference Network for Rare Eye Diseases: The admission of 28 new members into the network at the beginning of 2022 takes us an important step closer to equal access to diagnosis, treatment and integrated care (medical, social, psychosocial) for people living with rare eye diseases such as Usher Syndrome, which is the most common cause of combined vision and hearing loss and deaf blindness, in all EU member states.

Austria has three Associated National Centres in the network (eye clinics at MUC Vienna, Graz, Linz). Integration into the national health care systems and a nationwide network beyond the borders of federal states will be crucial for the success and the full benefit for patients. Also, national and European health registries within the European Health Data Space will play a key role, but be a major challenge for member state and the European Commission.

Another focus of the network in 2022 and 2023 will be the development of Clinical Practice Guidelines, position papers and consensus statements for the management of syndromic and non-syndromic eye diseases to be applied in all EU member states. Also, education and training of future experts is being done with the aim to implement expert knowledge and the standard of care all over the EU. In these activities ePAGs (European patient representatives) are involved and make the patients' voice and perspective heard. Learn more about the mission and goals of ERN Eye here: <https://www.ern-eye.eu>

Why is this important for the CI community of patients, patient experts, leading health care professionals and researchers? Closer collaboration in specific projects and their expertise and application for membership in the ERN CRANIO/ENT (including genetic hearing disorders) would be very useful in order to foster an interdisciplinary approach ENT/Genetics/Eye at national and international level, following the model of the French Eye and Ear network Sensgene. Learn more here: <https://www.sensgene.com/en/> and here: <https://ern-cranio.eu/the-network/>

RIWC 2022 – Retina International World Congress 8-11 Jun2 2022, Reykjavik, Iceland, joint event with NOK- Nordic Congress of Ophthalmology

Highlights of the congress can be viewed and read here:

<https://retina-international.org/wp-content/uploads/2022/07/Final-RIWC-2022-Publication.pdf>

RI's main focus of 2022 is their work with political stakeholders to implement equal access to an accurate diagnosis of Inherited Retinal Diseases (syndromic = combined for ex. with hearing disorders, and non-syndromic) through a genetic diagnosis worldwide.

You can read the report of RI's Genetic Testing Taskforce here

<https://kyc.retinaint.org/wp-content/uploads/2022/06/Retina-International-Genetic-Testing-Taskforce-Report-Final.pdf>

Poster “Do’s and don’ts on Usher Syndrome” at ECRD – European Conference on Rare Diseases 27 June -1 July 2022 Online

The following poster on Usher Syndrome was presented as part of ERN eye's Best Practices Series in the theme “Rare Disease Patient Groups Innovations”:

<https://my.ltb.io/www/#/>

The European Conference on Rare Diseases takes place every two years and gathers patient representatives and organisations and from national and EU health authorities, researchers and scientists, industry, regulators and payers and other relevant decision makers and discusses implementation of the EU Rare Disease strategies at national levels via National Action Plans for Rare Diseases.

USH2022 – Usher Connections Conference 8-9 July 2022, Austin, Texas, USA and Online

For the first time after the pandemic the conference could be held as an in-person event (hybrid) giving an overview of research updates and clinical trials and offering breakout and virtual parents sessions on both conference days. Registered participants (in person and online) can view and read the presentations and recordings here:

<https://www.usher-syndrome.org/ush2022.html>

Usher Awareness Day 17 September 2022

Global Usher Awareness Day was initiated by the US-based Usher Syndrome Coalition. Each year around the equinox on the third Saturday of September, Usher families and organisations across the globe raise awareness of Usher Syndrome, the most common cause of combined vision and hearing loss and deaf blindness, and organise events and social media campaigns with the aim to connect Usher families worldwide and above all, to promote research and therapeutic development and to find a cure for the progressive vision loss leading to blindness and deaf blindness.

12th National Congress of Rare Diseases, 23-24 September 2022 Linz, Austria
(Österreichischer Kongress für seltene Erkrankungen)

The event focusses on the implementation of the EU Rare Disease strategies in the Austrian Healthcare system in order to enable high level diagnosis, treatment and integrated care for patients living with a rare disease such as Usher Syndrome in Austria. See more here: <https://www.prorare-austria.org/news/veranstaltungen/event/12-oesterreichischer-kongress-fuer-seltene-krankheiten-2022/>

ERN-Eye Scientific Workshop, 1-2 December 2022, Ghent, BE

While the spring meeting was focused on the strategies and projects of ERN Eye, the winter workshop will be dedicated to research and science and clinical trials in the Eye space.

Contact

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<https://www.facebook.com/ushersyndrom>

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WORLD NEWS – Usher Review of events 2021



Author: Dominique Sturz, Patient Advocate Usher Syndrome & Rare Diseases, ePAG ERN-Eye (European Patient Advocacy Group European Reference Network for Rare Eye Diseases), Usher Contact CIA (Cochlea Implantat Austria); Usher Initiative Austria

In 2021 a series of international high-level conferences was held in an online format due to the pandemic. You can access the presentations under the links provided below.

USH2021 Usher Connections Conference 12-15 May 2021

Organised by the US based Usher Syndrome Coalition, a joint event with the Scientific **Workshop der Usher 1F Collaborative** about Therapeutic Strategies for Large Protein Coding Genes in Usher Syndrome, and co-funded by the Chan Zuckerberg Initiative.

FFB USH1B Scientific Workshop 13 September 2021

Online Workshop organised by the Foundation Fighting Blindness US within the support of Save Sight Now. Key areas discussed were disease mechanisms and clinical presentation, animal models and therapeutic innovation in the field of Usher 1B. You find the presentations here: <https://www.fightingblindness.org/usher1b-workshop#presenters-1009>

Usher Info Scientific Symposium 6-8 October 2021, Online

Symposium organised by the French leading experts of Usher Syndrome gathering the international leading Usher experts from the Eye and Ear space and from Human Genetics as well as patient experts and representatives. The recordings and presentations can be accessed here:

<http://pro.usherinfo.fr/usher-info-symposium-2021/replay-vod/scientific-symposium/>

Usher Info Patient Symposium, 9 October 2021, Online

Summary of the highlights of the conference for Usher patients and their families, research updates, psychosocial aspects and patient stories (lived experiences).

Conference language French, automatic captioning in 23 languages supported by **Usher Syndrome Coalition**

Recordings and transcripts can be accessed here:

<http://pro.usherinfo.fr/usher-info-symposium-2021/>

Links to earlier important Usher Information:

<https://www.retina-international.org/wp-content/uploads/2020/04/RI-USH-Newsletter-PDF.pdf>

<https://www.retina-international.org/resources/usher-syndrome-special-interest-group/>

<https://www.retina-international.org/wp-content/uploads/2020/04/RI-USH-SIG-Winter-NL-2019-final.pdf>

<https://retina-international.org/retina-international-newsletter-spring-summer-2019/>

<https://www.retina-international.org/ri-ush-sig-precautions-and-recommendations-for-people-living-with-usher-syndrome-during-covid-19/>

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WORLD NEWS – BELGIUM – Vestibular Infant Screening-Flanders



Photo: ©VIS-Flanders. Vestibular screening in a 6-months-old baby.

First vestibular screening program for babies with hearing loss

In 2018, Flanders was the first region in the world to implement a vestibular or balance screening program for all babies with permanent hearing loss. As a result, vestibular problems in Flemish babies with hearing loss no longer go unnoticed and untreated as vestibular problems can affect the child's motor development. The results of this unique vestibular screening program reveal how often vestibular problems occur and which babies with hearing loss are more likely to have vestibular problems.

Implementation of the vestibular screening

In Flanders, which is the northern part of Belgium, hearing screening is offered to every newborn (± 60.000 per year) during the first weeks of life. In case of an abnormal result on the hearing screening, the child is referred to one of the centres specializing in hearing loss in young children. Each year, these centres detect a permanent hearing loss in about 120 Flemish babies. As the hearing organ (or the cochlea) and the vestibular organ are both located in the inner ear, babies with hearing loss have a higher risk of damage at the level of the vestibular system. If the vestibular system does not work properly, this can have a negative impact on the child's motor development, such as a delayed acquisition of their gross motor milestones (for example: learn to roll, sit, crawl, stand and walk). Therefore, early detection of vestibular problems is important to timely counsel parents and to refer the child to a physiotherapist for motor assessment and therapy if needed.

Unfortunately, vestibular assessment in very young children is limited in clinical practice. In order to detect vestibular problems at an early age and to increase awareness among health care workers and parents, the Vestibular Infant Screening (VIS)-Flanders project was started in 2018 by the Ghent University (department of Rehabilitation Sciences) and the Ghent University Hospital (Ear-Nose-Throat department) (<https://vis-flanders.be/en/>). As a result, a vestibular screening is offered to every baby with hearing loss in Flanders around the age of six months, prior to possible cochlear implantation. This screening is performed in the same centre that

provides follow-up for the child's hearing loss. Due to the strong collaboration between all centres specialized in hearing loss in young children, Flanders is the first region that has successfully implemented a vestibular screening program for babies with hearing loss.

How do we screen babies for vestibular problems?

The cVEMP (cervical Vestibular Evoked Myogenic Potentials) test is used as a screening tool to detect vestibular problems (cfr. image). This is a short and child-friendly test that examines the function of one of the five parts of our vestibular organ, called the saccule. The saccule plays a crucial role in the detection of gravity, which is important during the acquisition of the first motor milestones. The audiologist places the baby on a sloping pillow and turns the head towards the parents, who are distracting their baby with toys. In order to stimulate the saccule, the audiologist holds a small vibrating device (bone conductor) behind the left and right ear. The function of the saccule is then presented by a specific waveform, measured with electrodes placed on the child's skin.

Results after three years of vestibular screening in Flanders

This study demonstrates that it is feasible to implement a vestibular screening program on a regional scale because almost 90% of all parents with a baby with hearing loss in Flanders participated in the past three years. This study shows that vestibular problems occur in 1 in 7 babies with permanent hearing loss. In addition, vestibular problems are more common in babies with a severe degree of hearing loss and in certain causes of hearing loss, such as congenital cytomegalovirus infection, meningitis, syndromes and malformations of the inner ear. Secondly, this study shows that the cVEMP test is a reliable screening tool to detect vestibular problems in young children with hearing loss. However, a more extensive vestibular examination with additional tests is recommended in specific causes of hearing loss (such as a congenital cytomegalovirus infection or malformations of the inner ear). Finally, the results of this project indicate that the first motor milestones are severely delayed in babies with vestibular problems on both sides. For example, they take their first steps at the earliest around the age of 2. It is mainly this group of children who need extra support at a young age.

By successfully implementing the vestibular screening, Flanders aims to set an example for other regions in the world and to increase awareness about this topic.

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[WORLD NEWS – UKRAINE – Supporting deaf children with cochlear implants](#)



From a small village in the UK, donations were requested to help profoundly deaf children from Ukraine with cochlear implants, who are now refugees in another country. Monika Lehnhardt and the Lehnhardt Foundation have a direct link to these children who are in need, so donations totalling €583 were sent to the Lehnhardt Foundation. By using these funds, educational materials were immediately purchased for these children and delivered to them.

Some lovely photographs and comments have been received from the parents of these children, and here are a few of the comments:

"No matter what life situation you find yourself in, the realization that there are people ready to support for free brings a flurry of positive emotions! Such incredible wizards. This morning our Arthur received a whole box of gifts for the start of the new school year! This year, he doesn't have his usual "first call" and "ruler", but he definitely has a firm understanding that people with big hearts live in this World! We sincerely thank you for such support! It's worth a lot! We wish you that the kindness of your soul opens the most difficult doors for you, peace, goodness and long life! We hug you! Thank you from the bottom of my heart!"

"This is thanks to you for helping the children"

"Thank you so much for the gift!!!! It is now such a strange time It seems that the children were pulled out of the socket. Before the war, it was different for us and other children. Go in for sports, study for something aspire to."

"I have three children. 2 daughters with CI and an adopted son with SA. I received the package. Thank you very much! Children are very satisfied."

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Deaf**Kidz**
INTERNATIONAL

DeafKidz International (DKI) are the co-ordinators of the BATOD Audiology Refreshers resource project. The resource, funded by the William Demant Foundation, will be revising the 2009 Audiology Refresher publication. The views of the profession about the resource are important to BATOD, DKI and our lead partner, BSA hence a survey was conducted in June. The published findings of the survey are now available to read in the attached BATOD article <https://www.batod.org.uk/wp-content/uploads/2022/09/Audiology-Refreshers-survey-of-professionals.pdf>

The survey highlighted that "The majority of respondents preferred the downloadable version of PDFs (63.01%); however, it was clear from the open-ended responses that people would like a resource that included an interactive web page with downloadable PDFs, videos and resources that could be used for training."

DKI will soon be commencing the working groups stage of the process. We look forward to sharing updates as the project develops over the next year.

If you have any questions about the resource project, please do contact exec@batod.org.uk

Teresa Teresa Quail

Co-National Executive Officer and Magazine Editor British Association of Teachers of the Deaf (BATOD)

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WORLD NEWS – UK – British Cochlear Implant Group (BCIG)



(Photo: Cambridge – a city renowned for its universities and architecture – and the venue for BCIG 2023!)

The long-awaited revised **Quality Standards** Cochlear Implant Services for Children and Adults will be published as an open access supplement with CI this Autumn. This thought-provoking and wide-ranging document supersedes the Quality Standards last issued in 2018. The new document has been worked on by a Special Interest Group of BCIG members from across the specialty and aims to be less proscriptive whilst incorporating the ‘new’ ways of interacting with patients that evolved during the dark days of Lockdown. Special thanks must go to Helen Cullington, Louise Craddock and Dan Jiang and all the team – it was a fantastic team effort!

The BCIG Annual Meeting in Cardiff in April brought a record number of people together to hear news of the latest developments and research in our field. It was great to finally welcome Catherine Birman, from the Sydney Cochlear Implant Centre, Australia, to these shores. Her presentation as the Graham Fraser Memorial Lecturer was inspirational and a reminder of the importance of collaborative working and of how much we can learn from colleagues. At the AGM, Professor Manohar Bance announced that BCIG has released funds for small research projects. The money is intended for seeding research and we look forward to sharing the fruits of this at next year’s meeting. Further details are available on the [BCIG website](#).

Save the Dates! The 2023 BCIG Annual Meeting will be held in the historic city of Cambridge on 13th and 14th April 2023. The theme of the meeting is “Current challenges and opportunities in CI”. A call for abstracts will be announced shortly.

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WORLD NEWS – UK – Reflecting, Exploring and making Discoveries with The Cochlear Implant Coach.



Photo: Stuart McNaughton

Earlier this year, I branched out to utilise my counselling skills to support adults and families interested in Cochlear Implants. As a bilateral Cochlear Implant user myself for more than 20 years, I felt I was in a unique position to leverage my training to support adults and families so I created The Cochlear Implant Coach and then later devised the REDJ Programme.

I have been a qualified Psychotherapist since February 2020. Since then, COVID-19 has struck and it was during this period that my initial thoughts around The Cochlear Implant Coach developed. Leaning on my psychotherapeutic experience and drawing on our COVID-19 experience, I saw how more of us used technology than ever before, primarily to stay in contact and to be entertained. And this is why we also want cochlear implants: they help us to connect and to access more of the world. I started to wonder, however:

**When a child is waiting for their cochlear implant,
who is supporting the parents?**

A quick call to four Cochlear Implant Programs in the UK confirmed what I suspected – psychological assessment and support was undertaken by existing Audiological staff in the team. Why is this important? It is important to me because, over the years, I witnessed a number of mental health concerns that I think could have been avoided, and all of these were during and/or after cochlear implantations. Given the enormous transition individuals go through to get a cochlear implant, I believe that psychological support should be mandatory for both the individual being implanted and their caregivers.

Under the REDJ Programme, I am now currently supporting five families and one adult. Due to client confidentiality, I'm not allowed to go into detail. However, what I have discovered has been quite stark. What was apparent in all of the individuals who had signed up to the REDJ Programme was fear: fear of surgery; fear due to uncertainty; fear on impact of their current life etc., which brings me to one of the reasons why I created the REDJ Programme.

As a young hearing aid user, unbeknownst to me, my parents' fears were constantly being 'projected' onto me which made me feel 'less than'. In our role as parents, we must try our best to avoid doing this to our children. In each of the families, they have all discovered that they were actively, but unconsciously doing this to/around their children. Given that the vast majority of children go on to do well with cochlear implants, this projection serves no long-term purpose, but immediately reduces the child's self-worth. Also, by not advocating positively for their child, a message is being sent out to family and friends that their child is 'less than' within the wider community.

The way I work involves having one session with the mother and the father separately, and this can really reveal the dynamic of the family. Fathers tend to be less open and less communicative while mothers fear more, express guilt more freely and don't feel supported by their partners in the way they would like. In this respect, The REDJ Programme is a holistic approach which listens to and supports everyone. We know that parents that express how they feel and resolve their issues will benefit their child and their family dynamic.

At the moment, the REDJ Programme is a private service, but I'm wondering if there are qualified therapists out there that might want to expand this into their regions? More importantly, I would love to learn if any recipients out there felt unsupported during their journey to hearing? If so, what kind of support?

You can learn more about the REDJ Programme on www.TheCochlearImplantCoach.com and please follow me on Instagram – [@thecochlearimplantcoach](https://www.instagram.com/thecochlearimplantcoach)

The Cochlear Implant Coach does not offer medical devices or advise on device selection.

Stuart McNaughton

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[WORLD NEWS – UK - Auditory Verbal UK – Power of Speech](#)



At Auditory Verbal UK we were delighted to again host our Power of Speech event at the House of Commons in June giving seven incredible deaf children and a very special teacher the opportunity to address those attending, including UK Members of Parliament.

Each young person showed what deaf children can achieve when they have access to early and effective support.

16-year-old Lauren Press (far left) who has cochlear implants and spoke at the event about her experience, said: "It was a real privilege to speak at the House of Commons to support AVUK and all the wonderful work they do. All the children were fantastic and inspiring, and I hope that collectively we have raised awareness about the importance of early educational intervention for deaf and hard of hearing children."

[Read more and watch the video here.](#)

At Power of Speech, we also shared our new research, Stepping Stones to Literacy, which shows deaf children on our specialist early intervention programme are attaining educational outcomes on a par with hearing children. [You can read the full report here.](#) The report includes some interesting graphs.

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[WORLD NEWS – UK - Auditory Verbal UK – Celebrating academic success](#)



(Photos from left to right: Beatrice Cadman, Dhyana Gopal & Molly Bowden)

We have been celebrating the academic success of children with cochlear implants who attended AVUK's family programme when they were young.

[Beatrice Cadman](#) (19) is taking up her university place to study midwifery this month after getting great academic results. She attended AVUK for three years graduating when she was five with listening and spoken language skills equivalent to a hearing child.

[Dhyana Gopal](#) (18) will be studying medicine after achieving fantastic results in her International Baccalaureate Exams. Dhyana and her brother are both profoundly deaf and attended AVUK as young children. She said: "I am so excited about starting my degree this year and being able to continue to grow and flourish, without letting my deafness hold me back. This has been made possible because of the truly inspirational work of Auditory Verbal UK."

[Molly Bowden](#) (16) is one step closer to her dream of working abroad and using her French language skills after fantastic General Certificate of Secondary Education (GCSE) results (six Grade 9s, two 8s and one 7). She now plans to study French, History and either English Literature or Maths at Advanced Level. Molly said: "Being deaf from birth hasn't been an easy experience however it has inspired me to become more resilient and has made me a stronger person. I am able to advocate and stand up for myself to ensure I am not held back from achieving my goals."

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[WORLD NEWS – USA – American Cochlear Implant Alliance \(ACI Alliance\) announces the latest course line-up and speakers for the upcoming Tuesday Talks webinar series, which highlights important information for parents, adults and others in cochlear implants and related hearing loss topics.](#)



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

Tuesday Talks are introduced by Cochlear Implant Consumer Advocacy Network (CI CAN) members who also moderate the Q&A. Presentations take place virtually from 12-1PM EST with an opportunity for attendees to interact with each presenter. All sessions are free to attend, captioned, and will be recorded and posted for free on the ACI Alliance website.

ACI Alliance launched Tuesday Talks in January 2022 with four webinars focused on late onset hearing loss, pediatric and adult programming, and the film Rally Caps. Those sessions are available for free on our website.

The 2022-23 Tuesday Talk series includes the following talks:

- September 13: ABCs of IEPs: Guidance for Parents of Kids with Cochlear Implants
- October 11: What Happens at the CI Activation?
- November 8: Cochlear Implants for Veterans: How the VA Provides Coverage and the Role of Telehealth
- December 13: What Happens During a CI evaluation for an Adult?
- January 24: What Happens During CI Surgery?
- February 21: A Focus on CMV
- March 21: What Happens During a CI Evaluation for a Child?
- April 18: Rehabilitation for Adults Post Cochlear Implantation Part 1 (Part 2 date TBA)
- May 16: Finding a Listening and Spoken Language Professional Who Meets Your Needs

ACI Alliance is a not-for-profit membership organization created with the purpose of eliminating barriers to cochlear implantation by sponsoring research, driving heightened awareness, and advocating for improved access to cochlear implants for patients of all ages across the US.

*Find full details and register at www.acialliance.org/page/TuesdayTalks.

Contact:

Laura Odato; Director of Operations and Marketing; lodato@acialliance.org; +1 (202) 263-9746

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WORLD NEWS – USA – American Cochlear Implant Alliance (ACI Alliance) – A Deaf Child from China to the Voice of Apple TV's El Deafo: The Power of Families



The American Cochlear Implant Alliance (ACI Alliance) has published the story of Lexi Finigan, a cochlear implant recipient who voiced the title character in the 2022 streaming series *El Deafo*. Written by Lexi's mother, Rosie Finigan, "A Deaf Child from China to the Voice of Apple TV's *El Deafo*: The Power of Families," is an engaging narrative chronicling Lexi's story through persistent parental advocacy and the strength of supportive networks, both family and professional.

Rosie recalls worrying about Lexi getting a late start with her cochlear implants and challenging conversations with schools about whether the options initially presented for Lexi were truly the best options for her. Rosie concludes:

"Through this process I have met the most wonderful people, some of whom I have yet to meet in person and others who have become lifelong friends. It has taught us important lessons and even shaped the path of my older daughter as she plans to go to college to become a paediatric audiologist. As a family, we have witnessed the miracle of modern medicine and what the support of a strong family can do."

One key to Lexi's success was the way the family took advantage of resources to support her hearing journey. From the initial support they found at the University of Miami, the Central Institute for the Deaf in St. Louis and the John Tracy Clinic to the summer programs at Atlanta Speech School and River School, they also turned to online support resources through Hearing First, AG Bell and several parent community groups including the Facebook group for Parents of Children with Cochlear Implants. Rosie noted that each of these resources taught them something unique or a new approach.

Find the full story on our website at www.acialliance.org/page/storiesaboutchildren.

Laura Odató; Director of Operations and Marketing; lodato@acialliance.org; +1 (202) 263-9746

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[WORLD NEWS – USA – American Cochlear Implant Alliance \(ACI Alliance\) – Updates](#)



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

[CI2023 Dallas Abstract Submissions and Conference Site are Open](#)

Submit an abstract for CI2023 Dallas: Cochlear Implants in Children and Adults. Mark your calendar for June 7-10, 2023. Visit the conference website at CI2023dallas.org. We welcome you to submit an abstract on your research for the conference which will feature keynote lectures, panel sessions, podium and poster sessions.

[Submit your Abstract Here](#)

[CMS Publishes Proposed Medicare Coverage Expansion for Cochlear Implants: What Comes Next?](#)

The long-awaited proposed coverage expansion for cochlear implants was published on July 6. Confirmation of the coverage expansion proposed on July 6 is expected in the Fall. ACI Alliance is developing materials to inform our various constituencies about the expanded opportunities for

Medicare beneficiaries who may benefit including the broad audiology community, hearing health publications, and the general public via major media outlets.

[Read More Here](#)

[Guidelines for Clinical Assessment and Management of Cochlear Implantation in Children and Adults with Bilateral & Single-Sided Deafness](#)

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

We are excited to share that the first two papers (on pediatric topics) were recently endorsed by the American Academy of Audiology. This is an important outcome and means of broadening CI interest and knowledge among all audiologists.

A newly published paper covers Guidelines for Clinical Assessment and Management of Cochlear Implantation in Adults with Single-Sided Deafness. [Read it here.](#)

[Read Papers & View Webinars Here](#)

[Listening @ ACI Alliance](#)

To expand awareness about cochlear implants and our own research and advocacy activities, ACI Alliance is launching a new monthly free online publication—Listening @ ACI Alliance. Listening is intended for a broad audience and is suitable for your patient community and professionals who are interested in cochlear implants but not intensively involved. Please encourage those who may benefit to sign up below.

[Sign Up Here](#)

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[ADVANCED BIONICS – Practice, learn and connect](#)



PHONAK 

HearingSuccess

Connect to the sounds of life

HearingSuccess.com

Phonak and Advanced Bionics have come together to offer the HearingSuccess portal.

Getting hearing devices is the first step to better hearing and to being part of the conversations that happen all around. However, not all of the challenges of hearing loss disappear after getting hearing aids or cochlear implants. Your brain needs to adapt to this new way of listening.

So what can you do in order to be more successful with your hearing technology? Set goals, learn strategies and practice listening to support your everyday communication.

Inside the **HearingSuccess** portal you will find activities, information and communities to support you. Practice at your own pace and build communication confidence as your brain adapts to hearing more sounds and conversations.

You'll get:

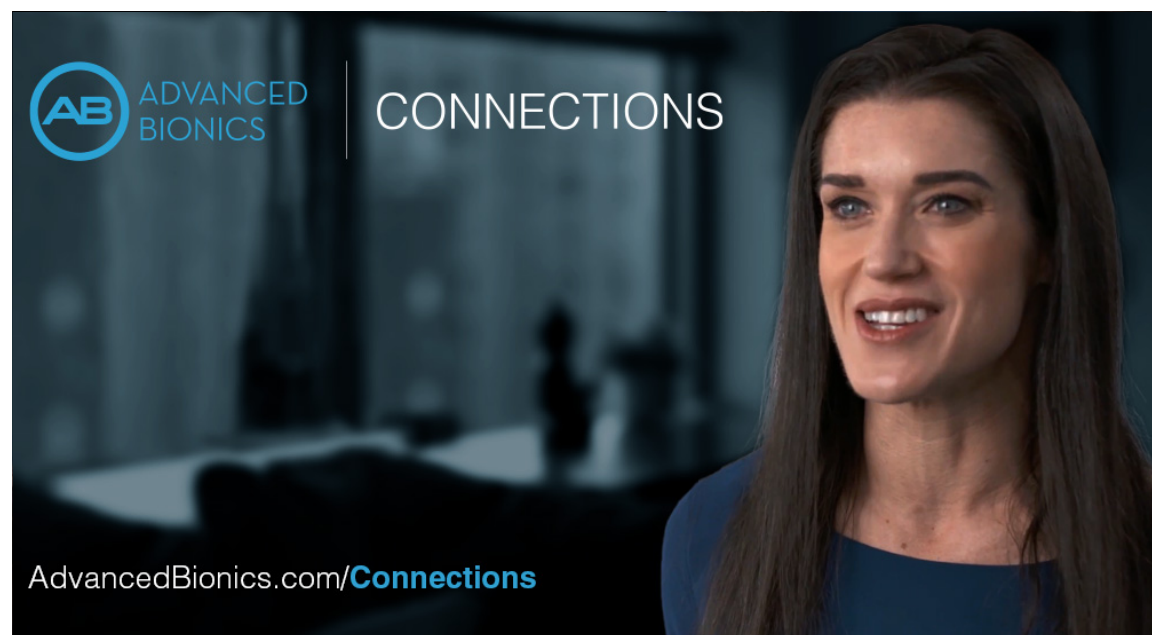
- Automatic visibility of resources
- Resources that are customized based on your specific needs, age, hearing technology
- Easy access to resources on a single webpage

Learning to listen with hearing technology takes practice! And the **HearingSuccess** portal will guide you. Moreover, all the resources are available at no cost.

What are you waiting for? Get started today at HearingSuccess.com.

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[ADVANCED BIONICS – My Cochlear Implants Enable Me to Continue Doing the Job I Love](#)



Rebecca Alexander is a critically acclaimed author, tireless disability advocate, practicing psychotherapist, and extreme athlete who is almost completely blind and deaf. See how she overcomes these challenges, and learn about her experience with Marvel CI in the remarkable story she has written for our blog.

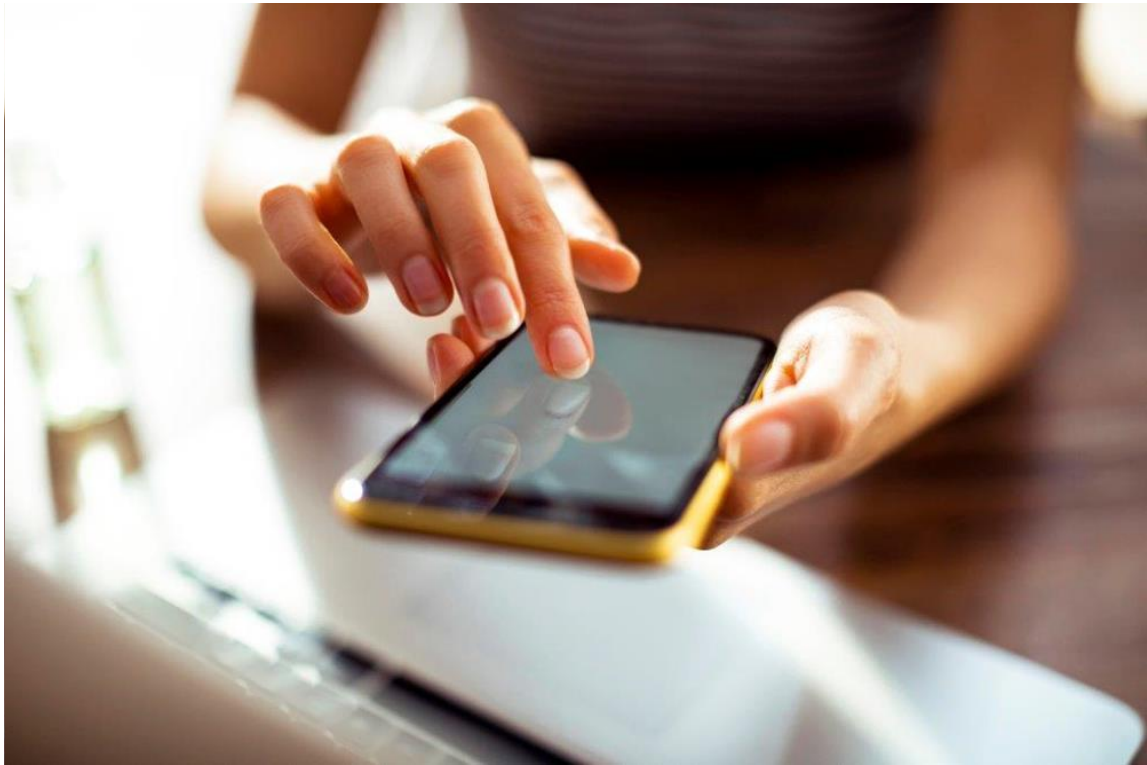
"It's hard to explain what the experience of going deaf and blind is like except to say that it has driven me to develop a keen awareness of just how precious time is. It's also allowed me to recognize how crucial it is for us to focus on what we have and what we can do, instead of what we don't have and can't do – Alexandra writes for us – For this reason, I didn't mull over or wait to get implanted. I knew that as my vision continued to decline, I would need to rely more heavily on my other senses to maintain my career as a psychotherapist, and to navigate my everyday surroundings."

Read Rebecca's full story on [CONNECTIONS](#), learn how much time and energy she put into relearning how to hear, and how she's now thriving with her CIs.

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

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COCHLEAR – Have you tried these mobile apps designed to boost your listening skills?



What's your favourite app? Do you like playing games, watching a favourite TV show, or scrolling through your social media feed?

You might be surprised to find some of your favourite apps can also help you improve your listening skills.

There are also loads of mobile apps designed specifically to help you live more confidently with hearing loss.

Self-managing your hearing loss is a key component of successful hearing therapy. **(1)** So it needs the right tools to make this possible. To help you navigate the many apps available, our hearing therapy team has put together this list to help you get started:

1. Practise listening

There are a number of easily downloadable audio book apps to help you practise listening skills. **Audible** (a subscription service) lets you download and listen to stories. **BorrowBox** and **Overdrive** are apps that let you borrow books online from your local library.

TED Talks are useful because of the huge variety of topics, voices and accents. All talks have optional captioning which you can follow to support your listening.

i-AngelSounds is an auditory training app allowing you to identify environmental sounds, the names of common foods and familiar animals, and monosyllabic words.

2. Cope better with noisy environments and social distancing

Apps that translate speech into text in real-time on your smart phone can be useful. The accuracy may not always be perfect, but these apps can be helpful to improve communication where social distancing, facemasks and noise make it difficult. Try these:

- **Google's Live Transcribe** is an Android™ app that provides free, real-time, speech-to-text transcriptions to help with everyday conversations. The app can also recognise non-speech sounds and is voice-activated. Live Transcribe shows speech and sounds as text on your smart phone screen.
- **Notes for iOS**. Use Notes on your iPhone to capture a quick conversation. Open Notes. Tap to start your new note. Then tap to start voice-to-text transcription.
- **Otter.ai** is available for both Android and iPhone. It is a subscription-based app, but free plans are available.

3. Manage your listening environment

Sometimes background noise can be overwhelming and spoil a social event like dinner out with friends or family.

Apps and online reviews can help you discover venues suitable for people with hearing loss. Try these:

- Find customer reviews on noise levels (as well as the food) when choosing a restaurant using **TripAdvisor** and **Zagat**.
- **SoundPrint** is a mobile app that takes a decibel reading and averages a location's readings so you can view noise levels when choosing a venue.

4. Safety and sound awareness

- **iPhone Sound Recognition Alerts** allow your iPhone and iPad to alert you to sounds, such as running water, appliances and doorbells. It can also identify shouting voices or a baby crying, and can distinguish between alarms for fires, smoke and sirens.
- **Android Sound Notifications** allows your Android phone to alert you to sounds via a push notification, a flash from your camera light, or by making your phone vibrate. Google says Sound Notifications can identify 10 sounds – from sirens and a dog barking to smoke alarms and water running, among others.

Check in with your hearing health professional to find out what digital tools are available. And ask them about their favourite apps as well!

To find out more about other resources to help to improve your listening skills, visit www.cochlear.com/uk/en/home/ongoing-care-and-support/rehabilitation-resources

References

(1) Convery E, Keidser G, Hickson L, Meyer C. The relationship between hearing loss self-management and hearing aid benefit and satisfaction. *Am J Audiol* 2019;28(2):274-284. doi:10.1044/2018_AJA-18-0130

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

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COCHLEAR – Five reasons why the Nucleus Smart App helps me live with hearing loss everyday



Since upgrading to the Cochlear™ Nucleus® 7 Sound Processor a year ago, Lewis has found the Nucleus Smart App to be a main benefit of upgrading.

The 34-year-old marketing professional, who works in Cochlear's headquarters in Sydney, shares five features of the app he has found most useful in managing his work (as well as keeping his wife happy).

1. Adjusting how much environmental noise I can hear

"The feature I use most in the app is adjusting sensitivity. When I use my phone clip, I wouldn't be able to hear my own voice if I didn't change sensitivity. I need to know if I'm speaking clearly, too loudly or softly. By adjusting the sensitivity, I can still mostly hear other people as well as my own voice in a way that's helpful. And when I'm streaming a video, I can take the sensitivity off if I don't want to hear any background noise, which improves the sound quality. I adjust this by selecting 'More' under Volume in the app."

2. Listening in a noisy environment

If you find yourself trying to have a conversation in a noisy environment, and have a sound processor that has ForwardFocus enabled, it can help you filter out background noise so you can manage face-to-face conversations.

"By selecting 'Program', I'll turn ForwardFocus on and it reduces noise coming from behind me which is fantastic when I'm in a noisy environment such as a restaurant."

3. Connecting to other devices

Lewis also uses the Nucleus Smart App to connect and switch between different devices, such as the Cochlear Wireless TV Streamer.

"My wife, Vanessa, often tends to work late in our living room. If I switch to the TV Streamer, I can watch TV without bothering her. I just select it through the app and she can't hear the TV at all as it streams directly to my sound processor. It's especially helpful for when a soccer match is on – I enjoy soccer, but my wife doesn't."

You can switch between devices by accessing the feature by selecting 'Audio Sources' and select any of the devices you have connected such as the Cochlear Wireless Mini Microphone, TV Streamer or your telecoil.

4. Learning how much of my day is spent listening

By selecting the menu, followed by 'Hearing Tracker' then 'Time in Speech' Lewis can see how much time he's spent in a speaking environment.

"I've learned through the app that I spend about six hours in speech on average each day. If I'm feeling especially tired, I use this feature to figure out if I spent more time in speech than usual. When I'm listening to people, I'm concentrating more and that tires me out more."

5. Knowing how much battery I have left

"With the Nucleus 6 Sound Processor, I was often nervous that my battery would run out at specific times, like during job interviews," Lewis says. "And if the battery runs low, it beeps which is very distracting. Instead of disrupting my work, using the app I can check my battery level easily, which saves me a lot of stress."

Being able to check the battery level using the Nucleus Smart App is a small but reassuring feature.

"There are apps I like more, for example I love Spotify to listen to music and AllTrails to find great walks around Sydney. But the Nucleus Smart App is one I would struggle to live without. It offers some simple yet important ways to adjust that allows me to control how I hear, and that's something most people can't do."

If you have a Nucleus 7 or Kanso 2 Sound Processor, you can use the Nucleus Smart App to tailor your hearing to your personal preferences, all from your compatible Apple or Android smartphone or Apple Watch. Download it for free via the Apple App Store or the Google Play store.

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

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

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The Cochlear Nucleus 7 Sound Processor and the Cochlear Nucleus Kanso 2 Sound Processor is compatible with iPhone, iPad and iPod touch. The Cochlear Nucleus Smart App is available on App Store and Google Play. For compatibility information visit www.cochlear.com/compatibility

For information regarding the compatibility of Cochlear's Sound Processors with True Wireless devices, visit www.cochlear.com/compatibility

ForwardFocus is a clinician-enabled, user-controlled feature.

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COCHLEAR – Cochlear Foundation seeks inspiring stories from children and young people.

Achieve anything program

According to the World Health Organization, 34 million children around the world live with disabling hearing loss. Without equal opportunity to a quality education and early access to hearing healthcare and support these children may not realise their full potential.

That's why Cochlear Foundation started the [Achieve anything program](#). In September 2021, the program was launched to invite children and young people with hearing loss to share their stories – shining a light on the experiences of young people with hearing loss, demonstrating the importance of early access to hearing healthcare, support and education.

Seven young people who share their stories will be invited to join Cochlear Foundation at the Achieve anything Global Summit in London, UK in May 2023. They'll be asked to represent their countries as national ambassadors of Cochlear Foundation's Achieve anything program.

If you know a child with an inspiring story, you can share it on the [Cochlear Foundation website](#). Their story will help promote the importance of having access to a quality education and early access to hearing healthcare and support.

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[MED-EL – Reliable Hearing by Design](#)



When you choose MED-EL, we know you count on us to hear everything you love every day. We're committed to providing you with reliable cochlear implants that meet the highest quality and safety standards on the market.

That's why MED-EL's devices have been developed with a complete view of reliability and safety in mind focused on five critical areas: **cochlear implant reliability, electrode safety, safe stimulation, MRI safety, and audio processor reliability.**

In fact, a recent study based on clinical data found that the probability that you'll continue to benefit from your cochlear implant after five years is highest with a cochlear implant from MED-EL.

[Find out why MED-EL leads in cochlear implant reliability and download the full report here.](#)

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MED-EL – Sound Sensation – The MED-EL Music Festival



On October 6-8, MED-EL is celebrating the musical talents of hearing implant users from all over the world with the Sound Sensation music festival. This event featured in the last newsletter but

now we have more details to share with you.

The free virtual event will include performances from musicians with cochlear implants, workshops on music training for hearing implant users and parents, and a series of music-themed webinars for hearing professionals.

Don't miss out on all the interesting online activities and events. Find the full program and more details on the multi-language festival [landing page](#).

And now let's take a sneak peek at the Grand Finale.

The Grand Finale

The Sound Sensation festival will end with the Grand Finale, broadcasting from Vienna on October 8. Be our virtual guest when hearing implant users team up with famous professional musicians such as an ensemble from the Vienna Philharmonic Orchestra, renowned violinist Yury Revich, singer Tom Neuwirth (aka Conchita Wurst), and others. Witness the sensational performances that show how people with cochlear implants can still make world-class music.

It's going to be a Sound Sensation! See you there. Don't worry if you can't make it on the day, all the events will stay online so you can stream then whenever you want.

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MED-EL – Even More MED-EL Users Can Enjoy Bimodal Streaming



Great news! With the release of Android 12 operating system, the number of smartphones that support bimodal streaming has been expanded. On the MED-EL website, you can find updated information about our latest connectivity and streaming possibilities including the new AudioStream, which allows you to enjoy bimodal streaming with your hearing aid and MED-EL cochlear implant:

Read more: <https://www.medel.com/hearing-solutions/accessories/connectivity/audiostream#bimodal> .

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MED-EL – Your Life, Your Soundtrack



Music is more than just sound; it expresses how we feel and connects us to other people, special places, events, and our culture. In fact, over 50% of us listen to music every day *, which is why MED EL has launched a new campaign with #YourLifeYourSoundtrack to celebrate music and raise awareness that 'music knows no age, neither does hearing loss.'

We care about everybody's hearing and how technology and rehabilitation materials can really help any hearing implant user to reconnect to the music that they love. Help us to spread the message and join the discussion at <https://go.medel.com/your-soundtrack> or our Facebook page [@medel.hearlife](#)

#YourLifeYourSoundtrack

* 12,762 global survey respondents age 18+, May 2022.

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