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## UK CoD

The BT Tower in central London was the venue chosen by the UK CoD organisation to hold its second annual conference.

This totemic building dominated the skyline of central London many years is now unfortunately closed.



Its unique feature of a revolving restaurant at the top was a big attraction for people not only be entertained but to survey the city of London such a unique position. It had been opened on the day for delegates to enjoy this unique perspective of the London skyline.

### The objectives of UKCoD are

- To encourage the exchange of knowledge, skills and views between members.
- To facilitate campaigning on overarching issues affecting deaf people.
- To champion the role of the voluntary sector and provide an interface with government for members.
- To provide up-to-date information about sector-wide projects delivered by members.
- To improve and extend cooperation between member organisations in promoting and representing the interests of deaf, deafened, deafblind and hard-of-hearing people.
- To provide a forum for debate and a focus for action on deaf issues.
- To promote understanding and acceptance of the different perspectives on issues connected with deafness.

Sheila Circo, Chair of UK CoD introduced a number of speakers who set out how their work was supporting those who have a hearing impairment irrelevant of its nature or scope.

She introduced Nicky Morris with Louise Goldsmith of the Deaf Blind a wonderful organisation on which unfortunately so many have to depend.

Gordon Hay said that the door had been opened with government about a deaf Olympics. This year the para-Olympics will be held in Paris following the full-scale event. John explain how steps were being taken to explore the prospect of a deaf Olympics as a separate event.



Our Ambassador ([www.nciua.org.uk/about-us/people](http://www.nciua.org.uk/about-us/people)) won a Bronze in the Marathon of Olympics 2013.

Robert Klein, independent adviser in mental health and president of the British Society Mental Health and Deaf gave a number of examples where professional organisations such as

those featured here can help people who have a hearing loss in so many matters not least of which are legal and applications for assistance at work. The entire conference was videoed and can be accessed at <https://ukcod.org/2024-conference-videos/>

BT continue to provide Relay UK (dial 18001) which is a free service for those who which to continue using it and Minicomms still also work as before.



Nigel Williams

## AGM

Nigel Williams reported that the Executive Committee had met several times in progressing the affairs of the Association. We've introduced a free membership scheme in which we ask applicants to make a donation to our funds.

We've continued to send out the Experience Booklets free of charge.

There is now an organisation of which we are founder members, the CIICA, the cochlear implanted international community of action. One of our presenters today (see Page XX) will talk about them. They had their first conference in May in Belgium which I attended, which was with people from literally all over the world.

Paul Tomlinson reported on the accounts which were distributed.

The bottom line is that during the year we spent £1,600 more than we earned which is a little bit higher than the normal going rate. Typically, I expect to see about £1,000 more going out than is coming in. Last year was very much distorted because that was the year in which we printed the new Experiences Booklet. So that obviously took us a good amount out of our reserves.

Corporate members subscriptions have not been followed up which basically means the CI centres and the manufacturers. During the lockdown they were all working from home and it really was too difficult to do business with them. So, there's about £200 or so to come from them this year.

Nor regrettably is the fact that we had planned a forum for Manchester in November last year which Richard had put a lot of effort into preparing and unfortunately a week or so before the event the numbers of bookings were sufficiently low that it just wasn't sensible to go ahead with it. This unfortunately meant that we were past the date of which we could cancel the room booking without any penalty. So, we have had, there is a cost there that is regrettable. We also, during the year, sent out substantial numbers of copies of the experiences booklet to CI centres.

Historically, we invited them to contribute to the quite substantial cost of posting these out, but we are very conscious that for the CI centres to process these charges decide how to take that forward. Nevertheless, overall the losses that we have incurred are well within our reserve capacity which is largely due to the very generous donation we received from Jenny Budge, Chair of the former Home Counties Support So as you can see at the year-end we had virtually £25,000 of reserves available. So, assuming that in this coming year we can get that rate of overspend down to a more normal level, there's no cause for concern.

We have to formally elect a Committee. The current members are all willing and prepared to stand. We've had two co-opted members this year who are now happy to stand for election. So, the proposed committee will be myself, Tricia Kemp as Vice Chair, Ray Glover as secretary, Paul Tomlinson as treasurer, Richard Byrnes as newsletter editor, and the two new members are Zrinka and Steve Rumball.

The vote was agreed.

Nigel Williams said he was more than happy to accept new nominations through the year to anyone who would be interested in getting more involved or finding out about it. As the two new ones did this year, we can co-opt during the year, and they can decide at the next AGM whether to stand.

## Fire safety in hotels

By Paul Tomlinson

One concern deaf people have when travelling is that they are very unlikely to hear hotel fire alarms. Currently it isn't practical to take your beloved cochlear implant to bed with you, so it doesn't give help with this particular problem.

Hence it is worth knowing that both the Premier Inn and Travelodge chains have equipped all their outlets with the Deafgard TM vibrating pillow alarm system. This has an acoustic sensor tuned to respond to a conventional fire alarm siren, it then triggers both a vibrating pad under the pillow and a fairly powerful strobe light.



You have to ask the reception staff to provide you with the Deafgard kit. The training the staff receive in where these kits are stored [and how to keep them equipped with healthy batteries!] can be rather hit and miss, but it is worth persisting in your enquiries, it is potentially a life saving piece of kit.



On behalf of Advanced Bionics, I would like to thank the organising committee for us to be able to share an update with you. My name is Richard Hughes. I work with AB as an education manager. So, in this presentation I will cover 2 main things. In terms of services and the new product that AB has brought out recently which is remote programming.

So, just to remind you, Advanced Bionics is part of the Sonova group. You may be aware that they have a number of hearing companies such as Phonak.

We are able to use the technology that Phonak uses in its hearing aids and wired systems to be able to produce advanced technology we want anybody who uses our technology to be able to have the best hearing experience and to do that in an uninterrupted way and for us to be a really good partner. We are the youngest cochlear implant programme the cochlear implant manufacture we have been around for over 30 years and now have over 100,000 people who use AB in 65 different countries.

Our latest product the Marvel CI is able to use Phonak's experience with the hearing aid technology because they have been used in over 2 million ears and we are very fortunate to be use Phonak's technology with our product.

And we have a number of unique different products with AB from an MRI compatible implant to the T mic which allows cochlear implant users to use the telephone in the normal way by pressing against the ear to be able to have a waterproof microphone with our technologies.

I will talk now about AB remote programming show you how this works in a quick video. (Video playing with subtitles)

The way it works, AB uses Phonak technology, and wireless technology, and so with the latest AB processor, Marvel CI processor, we're able to use the Bluetooth plugs that the processor has so that the app on somebody's smartphone would be able to make changes wirelessly to the processor. So, anything that audiologist wants to do in real time, in terms of programming, that would be able to do with that processor. And in terms of



*Richard Hughes*

the smartphone people ask which particular type of smartphone can use this app? And it's not the smartphone itself but to do with the operating system.

So, with the Apple, IOS, it has to be IOS11, and with an Android 6 which was been out for ten years. So hopefully most people who are using a smartphone will be able to use that particular technology. And in terms of the benefit for people using this technology, here's a quote from somebody."

It brings it home for you in terms of the hassle of being able to go in to a hospital appointment and be able to travel in, to be able to have to pay for the car park and take time out from your lives." So hopefully with the app that will make it much, much easier and much more straightforward. So, what we're doing at the moment is to train our centres regarding this and to install the software, so if you have an AB device and a Marvel CI processor and are interested in this, please contact your CI Centre and they will be able to tell you about it. We want to make it as easy as possible for people to have the clinic programming sessions, and you can work around your appointments.

#### **Another quote**

"I had my first week mapping appointment this week using this technology. So, it was great. I was at home I didn't have to take too much time off work. The challenge was I wouldn't have been able to have the appointment if my husband hadn't been there because there were no subtitles. So, there was no way I could hear what the clinician was saying.

We as a company have looked at different apps, which do speech to text translation, so, obviously, you would choose a particular app that you would find most useful. A company does something called X ray Glass.

Everybody has a favourite app, but X ray Glass is very interesting. So please get in touch with us to learn more.





We are one of the leaders in cochlear implant technology. We had the first cochlear implant, we were the first to collaborate with Apple, Google and Amazon. We have invested more than 2 billion Australian dollars in R&D. We have the highest IP rating, so they have an IP68 rating on or Nucleus 8, and our other sound processor. So those of you that aren't familiar with IP ratings, that is the same level of water protection that your Aqua Plus has. So, if I push you into a swimming pool, be rest assured that your sound processor will still work afterwards, which is great.

We have got more than 600,000 people with one of our devices. And, actually, three or four people that have a cochlear implant will have a Cochlear implant. We were the first to offer direct streaming, and we also have the world's thinnest cochlear implant and the smallest and lightest sound processors. To start off with, I want to go over the a few of the key features that we have with our newest surround processor, the Nucleus 8.

For those of you that are waiting to have an upgrade, the exciting thing with the Nucleus 8 is we did change the shape as well, so it's designed to be more comfortable to sit on the ear, and it's smaller and lighter than the Nucleus 7. We also have the newest technology inside the Nucleus 8 surround processor, so it's designed to work better in those more challenging and noisy environments to hear the best. We also changed our feature for noise management which is called Forward Focus. So, with the Nucleus 7 if you are someone that has that, you may be able to turn that on and off using the app if the audiologist has activated that for you. We now have got that working automatically automatic time in the background with the Nucleus 8. So, it's really designed to help you in those challenging listening environments and attenuating that background noise that might be interfering with the conversation that you're trying to have. I know it was quite difficult in that room before, so if anyone has forward focus, you can have a go at turning it on. We also have the newest Bluetooth audio chip in the sound processor, and you can continue to make use of our connected care options which I'm going to talk about in more detail soon.

We brought our smart app in 2017 when the Nucleus 7 was launched. And in 2019, we introduced what's called the Remote Check. There's also the option of the audiologist making some adjustments to your sound



Louise Allan

processor using another tool which we brought out in 2022 called Remote Assist. This is a feature where they can activate your Forward Focus if it hasn't been turned on before. That will save you a trip from going into the implant centre as well. And then last year, we have another brought out a new surgical tool, so probably

less relevant for you in the room that have this already had your implants, but for those that might be going through a new implant, this is a great surgical tool that gives the surgeon real time feedback on how they are inserting the electrode. They will do a lot of tests, and it will send the information to the audiologist to go and switch it on for the first time. Really exciting technology, and it's all talking to each other.

What is Reality Care for? It's for those that need to travel long distances or have busy lifestyles. When you have to think about time off work, or someone to take you to the appointments. How many people travel more than an hour to get to their hospital appointments?

I have a video here is just showing you what might happen if your audiologist sent you a remote check appointment. So, what happens is they will send you a notification to do a remote check which you do through the App and you will do it in your own time. They can pick what part, what activities that it wants you to complete. They'll get you to fill in a questionnaire to see how you will be sent off with your different listening environments. They could ask you to do an aided audiogram check and the sound will be played to the sound processor and get a baseline of your hearing through that. Through the App as welcome can run an implant check to make sure all the electrodes are working really well.

So that's a really great tool actually if you've got, you know, someone might have had a bang to the head, amazing paediatrician population, fallen off in the playground and one can't get to to the hospital quickly mum can check that everything is functioning side. They can do a speech and the noise line test that audiologists can do. They will be able to see how you are scoring and compare it with your future appointments.

So based off that Remote Check, if everything is looking really well, the audiologist might say you sound like you are doing really great. Let's have another check in in a year's time and that could save you coming in for an appointment but if you were having trouble they might want schedule a remote assist consultation and they can adjust your map remotely or might want to bring you back into the clinic to have a face to face appointment.





Holly Loach

# BBC

I work in TV, live in London and have two implants. I lost my hearing at 14 months old due to meningitis, and I got my first cochlear implant at 18 months, and my second at 8 years old. And I'm really grateful for my implants. They're my lifeline. They're really the reason why I can live the life I have today. And when I first lost my hearing, it was quite overwhelming for my parents.

I had a lot of really strong rehabilitation programme at the time with speech therapy. My parents are musicians, so I was very influenced by music. It was compulsory to play piano. I didn't have much choice, but I do enjoy it. And my grandma used to read a lot of books, and so I accessed a lot of language through books.

I had in lots of ways quite a normal childhood. I went to mainstream school, and I had a group of hearing friends with whom I felt similar. I went to Bristol University to study English because books were just a big part of my life from when I was younger. And I am working in TV now.

And I think when I look back after I left University, I got a job as a PA at a production company which is quite a stressful job, managing diaries and being in an office and moving schedules around.

Now I'm working at a production company that produces factual entertainment. In my current project I'm working with Rose Ayling Ellis, a deaf actress who won the programme *Strictly Dancing*. We have the series producer who is deaf and has an interpreter, and we have a deaf commissioner and me. The rest of the team are hearing.

We have Zoom meetings that connect young adults with cochlear implants all around the world. And we have different topics, so we had topic transitioning to the workplace. We did one about what we can and what we can't we do with our cochlear implants.

We did one about travelling with cochlear implants. We did representation in the media. We have been working on a young adult report and advisory group survey, and we have a work in progress for change document which is basically a document that has really collated what all of this specific things that have come in up in the conversations, and it's been quite a challenge because everyone's from across the world, and we're making it a universal document but also not making it really generalised and obvious. And making it having that specific nuanced structure to it.

And sometimes it feels like it's not always been with cross referenced, or we've not always been involved. And that's because we've been children, and now we're in our 20s. But we think it's important that we are involved in every decision, and every conversation always comes back to the real experiences of people with cochlear implants. Because cochlear implants are just very complex. No one knows it all, and it's got to be about the person and the individual and how we engage with our cochlear implant, it's like a relationship that we have for life, and it's something that we have to sort of think about in the context of that as opposed to being just a piece of technology.

I had never known how mapping works. I'm going to learn and when I go to audiology appointments, I'm thinking, what do I need, how can my implant be tweaked to make it personal to me. And that's something an audiologist has never spoken to me about. So we really need to make sure that Universities and schools are really proactive in asking what cochlear implant users need.

It's also that we want to be treated as we are, we are not just a hearing person. We are not just a deaf person. We have cochlear implants and but we need ongoing support and awareness around what we might need, and having sort of being open minded as to the fact that our needs fluctuate and change, and as a real sense of the full spectrum. I think that being listened to is changing and I think it's improving. I think the world is becoming more open, but I think at the same time cochlear implants wearers as the devices get better and better there is greater risk that our needs become more overlooked in a sense.



Tony Murphy

# Auracast

Bluetooth is one of the most useful technologies created in the last 30 to 40 years. Originally developed by The US military for secure short-range communication. It developed into consumer devices from phones and many other sectors. It is now used in one form or another in almost every facet of life from medical devices to toys. Currently there are around 6 billion Bluetooth devices that contain some form of Bluetooth and this number is increasing exponentially.

Bluetooth is not a single technology. It broadcasts in the same frequency band, but there are 30 different forms or “Profiles” as they are termed. The technical specifications are created by Bluetooth SIG (Special Interest Group) a non-profit organisation which creates Bluetooth standards that all companies can use, to maximise the compatibility. Different profiles are optimised for different tasks. Battery usage is always an issue. Sometimes high quality is not a necessity.

You may only be sending data, such as a car fob or using a Fit Bit. Quality is important if you are listening to music, or live speech. The speed of processing is a factor, as you do not want the lip pattern of the person speaking to be delayed in respect to the audio from the AV system. This is termed “latency” and is relevant for hearing related disorders. The other aspect, is that Bluetooth can only be sent from one transmitter to one receiver. This is limiting for public broadcast.

To address these issues a new profile has been created: Bluetooth Low Energy Audio or Auracast. As the name suggests it is designed to use less battery life, send information between multiple devices and maintain a higher quality. It has the potential to create many useful features. Broadcasting to multiple people in cinemas or concerts. Broadcasting in multiple languages, public transport and sharing information between multiple users. It could replace loop systems as they are prone to interference, loops are older technology and thus difficult to automate.

With all new technologies, there will be a transition period for implementation. It is unlikely that a company or venue will immediately remove all their loop systems and move to Auracast overnight. There are practical considerations, it can be that new technology, can be promoted as it’s something different to talk about, this can be based on possibilities for the future and conjecture rather than fact. From a financial perspective any company must see a return on investment. With newer technology, which company is willing to invest first? This can delay implementation as all companies wish to ensure that there is a real market to sell to. Certainly, Auracast does offer huge potential, particularly with hearing technology but there are many practical and technical hurdles to be overcome. It would seem that a smart phone needs to be used to select which channel you wish to listen to. The transmitters will broadcast over a long distance, so how can this be managed? Latency, on the current specifications, seems to be high so it may not be useful for live speech. In terms of compatibility how do you know if your equipment will be compatible with the environment you are in?

There is implementation in small number of sectors. The Term “Auracast ready” is common place. The reality of what this actually means is potentially complex. There are only a few Smart Phone manufactures that have implemented Auracast. This is important as without this, Auracast cannot be implemented on wider scale. Auracast is a standard to create the maximum compatibility across all sectors. However, for smaller devices such as hearing aids or implants this could be technically challenging.

It could be as with past Bluetooth technologies that some manufactures may decide to create their own versions to overcome some of these technological limitations. This creates other issues as, how do you know which hearing device will work with which technology? Hence potentially confusing and no doubt frustrating for the user.

In conclusion Auracast may in the future create many useful features. Particularly for the hearing loss. In its present form this is more limited to public systems rather than live speech. Implementation on a wide scale is potentially at least 5 years away. Technology always improves with time, so many of the enclosed problems may be resolved. It is hoped that all manufactures will be able to adopt the same standard to create a more universal solution. If this can be achieved it could replace loop systems but it will not replace all current technologies and will probably be more an additional technology rather than a replace all concept.



# BEARS PROJECT

## *Behavioural Work with Deaf Children*

Marina  
Salorio-Corbetto Bears

I want to tell you about a project that we have that uses virtual reality games to support bilateral cochlear implants. The project is clinical trial at this stage across the UK. We are including children aged 8 to 16, and we are using games to train speech and noise, localisation of sounds, and also spatial music listening.

What is quite important about this project is that it's the first national health research programme for behavioural work with deaf children. There's a big team behind the project. There are people from the University of Cambridge, Guys and St Thomas', Imperial College and Southampton.

Listening to ears help us to locate sounds in space and to understand speech in noisy places. Children and young people are the biggest group of people with 2 cochlear implants. There are some adults as well but having two implants doesn't always get you to get the most advantage of them. So, there are still things to improve and especially as this group of children and young people spend a considerable amount of time in noisy places. So, some work is needed to help them to listen better. What I like about this project is that we have had a lot of interaction directly with groups of children and people with cochlear implants. They have told us at the very beginning of the project what were the things they needed us to do in terms of research. What did we need to find out in order to get the best outcomes for them?

Every day communication is tiring is challenging and requires extra effort and specially to combine the information from both devices in noise. Some of these children and young people even reject their second implant especially if they had first one and then later on the second one.

They also said that the current way that children are offered rehabilitation, doesn't probably suit their lifestyle that well and that they would prefer computer games of course. Not surprising.

So, there is a need to support the listening skills. We know that having two implants is better than just having one, but still for language development, for locating sounds in space, for understanding speech in noise, there is still space for improvement.

There are no clearly defined ways of programming two implants. They are usually programmed separately and when we do listen tests in the clinic they are normally done with one implant first and then with the other but not with them together so that's another thing that the project is changing.

I think these games may work and may help children to develop the skills better and why do we think that? Well, because of brain elasticity we know that if you practice there are studies showing already spatial hearing can improve with training and also listening in noise.

There are going to be 384 children involved. At the moment there are more than 110 already taking part. 70 of them have completed the 3-month point. That means some of them will have played for 3 months. Others simply do the usual interventions, they attend their clinical appointments, they do the same study appointments but they don't play the games.

70 of them have completed these so it's really good. What are we looking at? What do we want to know? Well we want to know whether using the games improves special speech in noise perception relative to use care. That would be normally what they do without the BEARS project.

We need outcome measures and the main ones are speech in noise. I think it's very interesting because as I schedule before, usually ears are evaluated separately when one goes to clinical appointments but with this listening test you actually have the 2 devices on and the sounds are played through head phones over the implants and people hear the sounds using their both ears. So, they can actually, we can actually assess whether they get advantage of listening with both ears when they are listening in noise.

We are not just measuring speech and quality of life. We also have a group doing qualitative interviews with children and families and we are learning a lot about their experiences. I think there is another, one thing is testing the interventions, do the games help or not which is interesting in itself, but for me, what is quite striking about the project is the way it is creating new tools for testing speech in noise in the clinic. Also, how much we are learning from just talking with these children and young people about their listening experiences.

The BEARS study is a National Institute of Health research programme. There is a centre helping deaf children, young people with bi lateral cochlear implants to listen in noise better. It's the first programme that responds to an intervention for deaf children at a national level and so far, we have 100 and then participants and 11 hospitals taking part. We are looking the children's listening experiences.





# SOUND Lab

*Dr Deborah Vickers  
Principal Research Fellow*

I am Debi Vickers from the University of Cambridge. And together with Marina Salorio Corbetto, we are going to give you an update on of the that we are doing at Cambridge.

So, our goal is to improve speech perception with hearing devices for adults and children who have hearing loss.

We use various techniques so we are looking at how the brain responds to different sounds. We are trained to use listening tests to understand how people are hearing with their cochlear implants and if there is anything that we can do to improve that. So, we pre-dominantly look at speech perception and music enjoyment, and music perception.

So, we use our measures to look at how we might be able to change device settings in one way to kind of optimise the way that we can send sounds to the ear. And we are also looking at training schemes to try and improve how people use the sounds that they receive.

We're a mixture of researchers, PhD students, master's students, clinicians, and academic researchers, and we work really closely with patients to help us do our research but also to help us interpret the findings so that they're relevant for patients. We always send summaries to people who've been involved so that they understand what we've done and the implications of the research.

So today I'm going to talk to you about some research from two people, this is Louis, and Cynthia. Louis's project is ongoing, and it's based on music but looking at sound quality of music, but also looking at sound quality for speech as well. So, it's characterising and alleviating sound distortions for adults using cochlear implants, a music engineering approach. So initially what he's doing is looking at two aspects. The first is

assessing sound quality with cochlear implants. With the intention of looking at the quality of music and speech. And looking at how this can change depending on individual characteristics, and I'll say a little bit more about that. And then second goal is to think how we can change sound quality if there's any problems. Can we make changes to the sound processor? Or are there things that we can do to help?

But it could be that people have their cochlear implants inserted differently. and that could affect which sounds are being sent to which parts of the ear. So, your ear likes to have the sounds in innately it's used to receiving. But there might be change because of where the electrodes sit. So what Louis is trying to judge if we can move the frequencies, would that be better for an individual person's ears. Would it be better to have the frequencies in a more natural place? If we can change the frequencies and send them to different electrodes, would it improve sound quality? He's using music examples and speech, and he's shifting the sound by an octave lower or higher, and it helps us to know if that would hip align the frequencies for you.

I want to tell you about Cynthia's project. She's interested in understanding how cochlear implant users hear sounds that are very similar. Can we discriminate sounds such as different notes and chords and looking at whether this affects somebody's speech perception in noise? How it affects music perception and music enjoyment.

What she found from the online work was that people find it easier to do this minor change which suggests that as these notes are getting together that's easier to discriminate that separating them which is a little bit counter intuitive. If you make them further apart, it would be easier to discriminate.



# Rugby



*Katie Denning*

I am a young daughter of my hearing parents. I am proudly deaf with profound hearing loss in both ears and bilateral cochlear implants. I had my first implant when I was 18 months old and my second 6 years later.

I am currently studying at Loughborough University which is known to be the best sports University in the world. I am in the first team quad. In the past I played junior for Cambridge senior championship for Shelford and representative rugby with Cambridgeshire, eastern counties and various individual teams. I had the privilege to play Wales in the England deaf women's team last year.

One thing I love most of all is Rugby which is a game of passion, sweat and blood. I love contact. I love getting trampled and trampling others in a cold wet mud. The burning joy of contact is why I love rugby. My father played rugby and he loved it. He has played in the back row and enforcer on the pitch. Known for their big tackles, and high injury rates, honestly, I think my doctors absolutely hate me. They only ask one thing of me. Do not play contact sport! I am my father's child unfortunately.

So I love the contact. I love the big games and even more smashing people in the tackle I was, blessed

with a nickname, at Cambridge rugby clubs I am known as the smiling assassin. Normally I wear both implants covered with a scrum cap. For England tests it is different. No one is allowed to use any artificial assistance. However, I am the only cochlear implant user in the current deaf squad. It is harder for me.

I do love playing without my implants. I can play without a scrum hat and the silence brings serenity into a pretty violent game. Even when wearing my implant, the reality is I can't hear much. When the ball is in play during the game I still wear my cochlear implant then when the ball is not in play it gives my teammates an opportunity to communicate with me. That is when I am glad I have my aided hearing and I am sure my teammates are too. There is always lots to discuss especially round the set piece. What is the line out or the backs move that we are going to use? What is the change of tactics depending on how the game is going.

Very important to me is my beloved older sister Maddi who is hearing. She went above and beyond to learn the basics of BSL and becoming fluent in the language I am so proud of her and we love the fact in a hearing setting we use BSL and are secret language to gossip about romance and drama. That's the sibling bond we love it.

To me there is no doubt that my journey has been especially made possible by having cochlear implants. They let me be a part of a team and access coaching whatever I choose to do. Overall, it's fine but my hearing is important as I am in the hearing dependent world. It makes everyone's lives so much easier when I can hear.

Even so, we are still very grateful for every single human being dedicated their time into helping us deaf people fit into the hearing world. I didn't choose whether or not to have the industry. My parents had to make that decision for me that I as a child could not make. As for that choice they made, I am extremely grateful.

I hope this has brought you an insight of me as life as a deaf rugby player. Next year I may be able to play in the Premiership alongside a host of other internationals. If I can do that the world is my limit.



*A report prepared by Paul Tomlinson, our Treasurer*

# British Cochlear Implant Group (BCIG) Meeting 2024

BCIG is the association of professionals who work in the field of auditory implants. Their annual conference was hosted this year in Gateshead by the North East Regional Cochlear Implant Audiology Department. Over two days a variety of presentations were made on developments in the field of auditory implants and discuss best practice.

The opening keynote address, given by Timothy Griffiths, Professor of Cognitive Neurology at Newcastle University was “Neurocognition - How hearing loss can cause dementia and the protective role of cochlear implants.”

It has been known for many years that there is a strong correlation between hearing loss and early onset of dementia, but nobody really understands the causality of the correlation. Which is the chicken, and which is the egg? If it could be shown that hearing loss is a cause of dementia and that by treating the hearing loss the onset of dementia can be avoided or delayed this would dramatically strengthen the case for provision of both hearing aids and CIs.

In addition to the quite heavy academic programme there was the usual Poster display which allows CI teams to report on their research work. Of mention is one specific poster, provided by Tracey Newman and her colleagues at the University of Southampton Auditory Implant Service entitled “Evaluation of Revision Cochlear Implantation -

Surgical and Audiological Outcomes”. We can be thankful that our implants have a remarkably good reliability record for such complex devices.

Nevertheless, as the number of patients with implants increases and the number of device-years grows it is inevitable that there will be a small number of users who find their device is failing. To have some solid data available on the success rate of re-implantation is a very welcome development. This particular poster was based on a review of 60 re-implantation operations performed at USAIS between 2013 and 2022, of which 78% were in response to device failures.

From a surgical perspective the great majority of operations achieved full depth insertion of the new electrode, with just a handful of cases where ossification resulted in partial insertion. Audiological outcomes were measured using the standard BKB sentence score tests, with most patients producing higher scores after re-implantation. Only about 3% of patients had significantly poorer scores than they had been achieving with the original implant.

Overall this study is very positive. If the UK Centres can work together to pool their data to create an even larger data set that would be very good news for CI users.





Efstratia

# RINRI

Rinri is a bio technology company based in Sheffield to realise cell therapy to treat hearing loss. I know advanced therapies have been in the news lately so I thought I would start by telling you a bit more what cell therapist and also what other advanced therapeutics are out there now.

Cell therapy and gene therapy are what we call advanced medicinal therapies and recently in the news gene therapy was featured. I don't know if you have heard about the clinical trial taking place in Cambridge. So that was a young girl who had a mutation in one of her genes in her inner ear in her hair cells and got a gene that replaced that and therefore, start hearing. So, gene therapy works when we identify a specific mutation. Then in the lab we make a gene that has the right information. We give that to the patients and hopefully that resolves the problem.

Cell therapy on the other hand which is also an advanced therapy medicinal product works on replacing tissues rather than specific genes and tissues are collections of cells that might be dying. With cell therapy you inject living cells that are restored the tissue regardless of the cost and at Riri we are working I don't know cell therapies for hearing loss. Does that make sense before I move on? Yeah. Okay.

So, as you very well know, currently we have hearing aids for mild to moderate hearing losses and cochlear implants for severe to profound. However even though they work miraculously and such great advancements we don't restore natural hearing and not disease modifying and especially for neural hearing loss we have no interventions. Now I'm going to go on to talk a little bit more about what neural hearing loss is.

So, you see here in the image we have in the green the hair cells and in red auditory neurons and there is a because conception that hearing loss is caused when we lose the inner hair cells or loss of the neural hearing loss has largely been in in order. Both are serious and both cause hearing loss and particularly neural hearing loss is associated with conditions such as progressive hearing loss or presbycusis that is as we get older and auditory neuropathy. I win talk a bit more about these 2 and why there are problems that we need to think about. Age related hearing loss is the most common form of sensorineural hearing loss and affects about 1 in 3 others over the age of 65. Adults. As we grow older that is there has been a lot of research in animals and humans that shows we lose 3 times more auditory neurons than hair cells and also that we lose auditory neurons before we lose hair cells and there is a strong correlation between loss of auditory neurons and our ability to understand speech. The graph on the side is from research that showed, on the vertical access we have how many words we can connect and on the horizontal access we have the survival of auditory neurons you can see even if you lose about 50 per cent you are still doing quite well but as soon as you lose that 50 per cent, then your speech understanding really starts to get worse.

Now moving on to auditory neuro that pi spectrum disorder affects about 5 to 10 per cent of individuals with mild to moderate hearing loss. Mix match between pure tone audiometry test that shows you have a little bit of hearing loss in the real life you might be experiencing a lot more difficulties.

It's caused by a disruption in the transmission of the sound from the ear to the brain and here is the pathway, so in blue is the inner hair cells and then down there at the bottom that is meant to be our brain so you get auditory neuropathy in any of that bath pathway is disrupted.

But there's different types of auditory neuropathy. There is a condition called synaptopathy. That results when you have problems with your hair cells and synapses. That is that bit there. Synapses is a connection between the cell. It is this bit right here. And examples of that are the gene that is the gene therapy that just came out. People trend to have good cochlear implant outcomes when they have these because it bypasses the inner hair cells and stimulates the auditory neurons if you have a problem and others then you don't really have good outcomes with cochlear implant because if you do get one there is no neurons for it to simulate.

So, what we are doing is we wanted to develop a therapy that would help with the problem of auditory neurons and here you see from our results. Here is an animal who has lost its auditory neurons and received the Rincell 1. You can see the new bodies and the cell in yellow and in red is the axle of the cells rejecting the inner hair cells and the brain and we hope that there is improvement 10 per cent will be clinically significant and we have been seeing more improvements in animals but that's quite different. Now we are developing the first clinical trial. This is the very long and official title but we want to make sure it's safe in people who have age related hearing loss and auditory neuro that they and going to compare 2 groups. One will get standard care which us a cochlear implant and the other group will get standard care and the cell therapy.

So, we will be checking for adverse events to make sure that people are not experiencing any. We are also going to make sure it is feasible to deliver it together with a cochlear implant because that's never been done before and also check to see if the auditory neurons survive if they are heal that in work the way they are meant to work and also if there is any residual hearing left. We will also look at whether the effects last. We might get that it works but who knows how long and also if it really makes a difference in real life situations by assessing quality of life and speech perception. The trial will last for 13 months where people will have a lot of safety visits and a lot of audio logical tests and using a tablet at home to record the health of the neurons themselves. And will be following people up in the future to just to make sure that you know, everything stays the same.

So next steps. Now we are going to have some pilot studies going on 2024. Will be submitting to the regulators for approvals in early 2025.

And if everything goes okay, we will be seeing the first patients in mid2025. And we will be workings with guys and St Thomas's here in London, in and a place in Newcastle and hopefully that will be a good geographical spread around the country last thing we have a study that going on this summer at guys and St Thomas where we are looking to develop new test to measure the health of auditory neurons. It will take place at that hospital. We are looking to recruit people who have an advanced, bionic cochlear implant for more than a year and 5 visits that will last about 3 or 4 years. The first will be a bit longer and the others a shorter and all travel expenses will be covered. There will be a gift voucher. If you want to want out more, if you know anybody that might be interested please come art wards back of the table at I can tell you more about it.



Julia Jensen

# MEDEL

*is an international company based in Austria*

This year we've brought out our audio stream adapters for the RONDO 3. If you want to look and see what it does and how it looks, it's here, so you're able to see it in action. But it allows you to stream directly to your phone as well. And we have a Hear Care app that has come out this year, and I think we've all be very aware of how life is evolving into remote and virtual, so we also have brought out our Hear Care app which allows the user to check the integrity of the implant.

So, you're able to download this app, and it will tell you if your processor is OK, if your implant is OK. If you perhaps bump your head or if you have a bad headache, you're able to fire up your app and check if your implant is working.

The Audio Key 2 app, as with all of our apps, whether it's on a laptop, computer, or phone, it's always important to update your apps. If you get a reminder that pops up on your phone and it says "update available", please do update your apps because it will affect how it works in conjunction with your processor. And then just a quick reminder of another useful resource. We're on YouTube, which is really useful for if you have any questions. We've got lots of hands on videos that you're able to access on YouTube. So, if you have forgotten how to change your microphone cover, or if you have forgotten how to do something, all of these

videos are hands on videos on, you know, Tube, so you're welcome to access that. We have a huge range of videos for rehab. If you feel like you're struggle a little bit with your hearing, you're just not processing this is as well, or you're having some difficulties, we have lots of rehab on YouTube. It gives you lots of tips and tricks and opportunities to practice your hearing at home. Which is really useful for when you are out there in the real world to do this practice. We have a blog. Please join the blog, and you can get lots of updates from us.

## Meludia

It's a really wonderful platform, and we have given our MEDel users free access to that. It's a separate platform or website, and it helps you have fun and play with music. So, it's devised to help you practice your listening skills, so you can listen to music better and experience it in a better way. So that's a really amazing app, and it starts really basically and as you work through it, it increases the difficulty. If you know of anyone who would like to get a cochlear implant or have just started their journey out, you're welcome to direct them to us, but also on our website, we've got these handy candidate packs for children and adults, and we've got the digital version on our website, but we also have physical copies, so if you'd like to post that out to anyone who is starting out on their journey, please do contact us. Social media. If you're on social media, we're there. If there's anything that we have mentioned like the audio stream adapter, that's a new product. So never fear. We're able to send that to you via our MED EL shop. So, we do have a shop online here in the UK. And we're able to send you any accessories or anything. Go online and order it, and we will send it through to you. And then just some final take home messages. We've got a real community of users which is nice to connect with. Regarding our Hear Care, we have a webinar coming up at the end of June.

## Contact

*Hopefully readers will have enjoyed this edition. What did you think about it? What did you like? What didn't you like?*

Please let me have your views so that the Newsletter can be improved.

Please contact me directly at - [editor@nciua.org.uk](mailto:editor@nciua.org.uk)

Thank you - Ed

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**Disclaimer** Whilst the Association uses its best endeavours to provide accurate information on the subject of cochlear implants it does not provide medical advice or make recommendations with regard to any particular implant or equipment and no article in this newsletter should be construed as doing so.

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