



NCIUA - THE WAY FORWARD

The Executive Committee of NCIUA at its recent meeting decided that a major review of the work of the association was needed. We need your help to decide on the direction we should take in future and how we can best serve the interests of cochlear implant users now and in the future.

Please read the article on the last page of this newsletter and send in your ideas and views about the future direction of the association.

CHOICE: Cochlear Home Care

A team from University of Southampton Auditory Implant Service has been selected by The Health Foundation, an independent charity, to be part of a £3.5 million improvement programme. The Scaling Up Improvement programme supports seven projects in the UK to take their proven health care interventions and approaches and make them work at larger scale to have a positive impact on patient outcomes. The initiative from the University of Southampton Auditory Implant Service will roll out successful telemedicine tools for adults with cochlear implants across the UK.

Dr Helen Cullington, Clinical Scientist at the University of Southampton Auditory Implant Service and Project Lead said, "People with cochlear implants need lifelong follow-up at one of only 18 centres in the UK. We are going to scale up a successful remote care pathway and offer the improvement to all centres across the UK. Patients can choose to use a personalised online support tool, home hearing test and support to adjust devices. We hope to see more empowered and confident patients, better access to care, stable hearing and a more efficient clinic."

The Southampton team hopes to roll out the tools to patients across the UK at the end of summer 2018. If you think these tools may help you, please contact your cochlear implant centre or get in touch with us. We are also looking for people to trial the tools at home before the big rollout, so please get in touch if you could help out.



Dr Helen Cullington

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DIARY DATES

The 2018 Summer Meeting and AGM will be held on Saturday 9th June 2018 at the University of London (Birkbeck Main Building), Torrington Square, London WC1E 7HX. Watch our website for more up to date information: www.nciua.org.uk

The University of Southampton Auditory Implant Service will lead the telemedicine project and will work in partnership with a wide range of organisations to deliver the project, including University of Nottingham, Northumbria University, Wessex Academic Health Science Network, The Ear Foundation and the National Cochlear Implant Users' Association.

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Technology Day 11th November 2018 at the Millenium Hall, Horton-cum-Studley, Oxfordshire

This event organised by Richard Byrnes and Michele Motteux was a great success. Although it was in the middle of the country there was very good parking and members came from miles around making it our best attended technology day ever.

Yvonne Noon from Advanced Bionics assisted by Michele Chemaly went through the latest technology for listening in challenging environments. Firstly, she spoke about listening on the 'phone. The first option is the T mic. There is also the in-built loop system and access to Blue Tooth devices using the ComPilot, which is worn around the neck. A new unique feature is the DuoPhone for two processors to communicate wirelessly. For those unable to use a mobile telephone there is the Easy Call for listening on the 'phone.

Hearing in noise has improved over the years as cochlear implant technology has developed. Users want to be able to hear in listening environments that are challenging. There is the remote mic working with ComPilot, the Roger system and in-built systems working separately or together such as Zoom Control and Ultra Control.

For music and the TV there is the Roger



Michele Motteux & Richard Byrnes

device, ComPilot and a TV link. Naida LINK bimodal hearing aid is the only hearing aid specifically designed to be used with cochlear implants and the only one that communicates wirelessly.

Jane Humphries, Oxford Auditory Implant Programme Co-ordinator, said that they were fitting mainly Advanced Bionic and Cochlear implants. For anyone implanted with Cochlear C124RE, C1512, C1522 and C1532 implants or Advanced Bionics C11 or later models after 2005 there were upgrades every five years if available.

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A few accessories were available such as the aqua kit and wireless accessories – ComPilot and a remote mic or the TV link, and DECT phone. Hearing aid users could continue with their own aid but Advanced Bionics had a new hearing aid, Naída Link bimodal hearing aid, which is designed to work with cochlear implants. Cochlear implant users could change to CNR sound stream hearing aids or high powered hearing aids which linked with Cochlear wireless accessories. Generally hearing aids needed to be fitted by specialist audiologists at the John Radcliffe.



Cochlear Workshop

Workshops were run by Cochlear and Advanced Bionics to demonstrate the use of the assistive devices.

MANUFACTURERS' NEWS

From Advanced Bionics

We are pleased to announce that the Advanced Bionics (AB) Sports Scholarship has been awarded to Peter Warman, who is training and preparing to enter the 8th European Deaf Badminton Championships in 2018 in Trencin, Slovakia.

Peter has been deaf since birth and his hearing has gradually deteriorated. In early 2017, Peter chose an Advanced Bionics cochlear implant which was switched on at the University of Southampton Auditory Implant Service (USAIS). "Thanks to Advanced Bionics and everyone at USAIS, I can now hear almost like a hearing person, the experience has been completely life-changing." said Peter Warman.

Peter is a Naída CI recipient and also uses the AquaCase™ accessory. Peter is a keen badminton player and applied for the AB sports scholarship so that he can achieve his dream of playing badminton on an international stage.



Peter Warman

"I have been training with the GB Deaf Badminton Team for a few years but I have never played for GB or England internationally due to the costs of attending, as it is self-funded. With the Advanced Bionics scholarship, I am now able to attend the 8th European Deaf Badminton Championships in 2018 in Trencin, Slovakia. This opportunity is something that I would never have had the chance to do otherwise. Thanks to AB!" said Peter Warman.

We would like to say a big thank you to everyone who applied to the Sports Scholarship and we wish you all the best for achieving your sporting ambitions. For more information, visit AdvancedBionics.com



Advanced Bionics

The Simple Way to Hear More

An Advanced Bionics cochlear implant gave Rachel the chance to hear again from one side. What solutions are available to get the most from both ears?



A Sonova brand

Rachel P., Naída CI AB Recipient

Hearing with Two Ears

Your complete hearing solution should take both ears into consideration. Wearing devices that work together can make it easier to hear the world around you. Hearing with two ears gives you a more balanced and focused representation of sounds. You can take advantage of the natural way that your brain interprets sounds and their location, making it easier to find and hear what you want to hear. Only the Naída CI can automatically create a wireless, ear-to-ear network with a hearing device on the other ear. This means you get a complete hearing solution and a fuller, richer hearing experience. Whether or not you have hearing in your other ear, there is a Naída solution for you:

The Naída CI Bilateral Solution

If you get minimal or no benefit from hearing aids in either ear, you should consider cochlear implants for both ears. Bilateral cochlear implants provide unique benefits that make it easier to hear the world around you.

The Naída Link Bimodal Solution

There are many reasons to continue to use a hearing aid in your other ear. Your hearing aid provides loudness and sound with depth. Your cochlear implant gives you greater clarity. When the devices work together, they can provide the rich sound you want and the speech understanding you need.

The Naída Link CROS Solution

If you hear with a cochlear implant in one ear but do not have any hearing in your other ear, you can use a Phonak Naída™ Link CROS to send sounds from that side to your Naída CI so that you can enjoy hearing your best in quiet and noise without having to reposition yourself.

The Naída Electric Acoustic Solution

If you continue to have hearing in your implanted ear, you will want to take advantage of this all-in-one cochlear implant and hearing aid solution offered by Advanced Bionics.

For more information on the different Naída solutions available, please visit AdvancedBionics.com or email info.uk@AdvancedBionics.com

RONDO 2 and SONNET: a choice of upgrade options from MED-EL

If it is time for you to upgrade your audio processor, MED-EL now has two great options: the new RONDO 2 and the SONNET.

RONDO 2: Easy to Use. Easy to Charge. Easy to Wear.

Changing batteries is history with the RONDO 2. This new single-unit audio processor includes a fully integrated rechargeable battery. No more carrying batteries; simply recharge your RONDO 2 overnight on the revolutionary wireless charging pad (similar to a charging pad used to charge a watch) and in just 4 hours you will have 18 hours of battery life.

This small and lightweight audio processor is worn off the ear, and easily hidden under hair or blends in thanks to a range of stylish hair-design covers. For more information about the RONDO 2 visit www.medel.com/rondo2

SONNET with rechargeable battery kit

Or, if you prefer a behind-the-ear option, why not choose the SONNET with a choice of wearing options including rechargeable battery kits. There are three SONNET rechargeable battery kit options: a micro battery pack, a standard battery pack, or a mixed pack containing both micro and standard options to provide complete flexibility for all lifestyles.

The 2.4GHz wireless ready SONNET offers a number of options to connect to external audio sources or assistive listening devices so you can listen to music on the go.

For more information about the SONNET visit www.medel.com/sonnet

Whichever option you choose you will benefit from MED-EL's FineHearing™ to bring you closer to natural hearing. MED-EL's Automatic Sound Management system will ensure you enjoy optimum hearing in all environments without manually changing programmes.

To discuss your eligibility for an upgrade to either the RONDO 2 or the SONNET please contact your audiologist/CI centre. For more information about the SYNCHRONY cochlear implant system visit www.medel.com.

Home Counties Cochlear Implant Group

How Did HCCIG Begin?

Back in 2000, three people with Cochlear Implants from North London decided there was a need to set up an informal group for Cochlear Implant (CI) users, their families, friends and for those awaiting implantation.

HCCIG Aims

Our four basic aims are:

- To exchange information about how we cope with our implants and the effect they have on our lives!
- To create a social environment where we can be with other people with similar issues.
- To give people awaiting an implant, or considering Cochlear Implantation, an idea of what it is like to have one and answer their questions.
- To raise funds to help and promote our group for the benefit of CI users, those awaiting implantation, as well as raising awareness of Cochlear Implantation.

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Who Are We?

Some of us are profoundly deaf from birth or childhood and use British Sign Language (BSL). Others have become deaf in later life and lip read, and some are just hearing friends, family or people with CIs or awaiting CIs.

What Does HCCIG Do?

HCCIG is run by deaf people, for deaf people who use CIs. We want to give independent peer support for those awaiting or considering a CI. We also try to alleviate the isolation and social exclusion of deaf people with CIs and their families and friends.

Finally we liaise with different implant centres, hospital audiology departments and CI manufacturers, to promote awareness wherever possible to the medical profession and any other people.

How does HCCIG do this?

Open meetings:

HCCIG hold open meetings, where practical. This allows all members the chance to attend and listen to professional speakers on issues relevant to CI users.

It is also a unique opportunity for all to network!

Wine bar and coffee meetings:

HCCIG members, family and friends or new people interested in joining have the opportunity to meet in a more informal setting. These events are dedicated to socialising and any other issues, problems or information can be shared.

Other leisure events:

We arrange events of interest throughout the year.

Future dates are published on Website www.hccig.org.uk



HCCIG social gathering

Foundation Study

The NHS provides a cochlear implant for adults with severe-to-profound deafness in one ear even though they are deaf in both ears. Two cochlear implants could help them to understand speech in noisy environments, to know where to look to see who is speaking and to avoid hazards outdoors.

The FOUNDATION study is looking for adult cochlear implant users to complete an online survey. The survey aims to gather your views about whether it might be possible to conduct a clinical

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trial comparing bilateral implants with unilateral implants for adults. NICE has asked for this trial to be conducted, and the FOUNDATION study is looking to see whether it will be possible to run such a trial in the UK. You do not need to have experience of bilateral implants or knowledge/experience of clinical trials to complete the survey.

The FOUNDATION study team would like to encourage any adult with a cochlear implant to complete the survey. The survey is also open to adults who are currently being assessed for a cochlear implant.

For further information, please visit <http://www.foundation-study.org.uk> where you can enter the survey. We would like to encourage all cochlear implant users to participate in this important research.

Captioned Theatre

However good our cochlear implants are for some of us enjoyment of the theatre proves difficult without help. I have enjoyed performances that have been captioned by StageText ever since it started nearly twenty years ago and go the theatre on a regular basis with my husband, friends and family. It is now accepted by most theatres that access for deaf and hard of hearing people means providing captioned performances as well as audio systems. Usually one performance of each play shown is captioned.

Some theatres rely on StageText to provide this facility but many, like the Oxford Playhouse and the Royal Shakespeare Company, do their own captioning. Although StageText have a list of captioned plays on their website www.stage-text.org.uk/whats-on it is not comprehensive and it is best to find our directly from your local theatre which

performances are captioned.

Most theatres offer tickets at concessionary rates (usually around £16) for disabled people and their companions. Seats, which allow visitors to have a good view of the captioning box, are usually reserved for deaf and hard of hearing people. If you want to find out more about captioned performances at the Royal Shakespeare Theatre go to www.rsc.org.uk/your-visit/assisted-performances ; for the National Theatre go to <https://www.nationaltheatre.org.uk/your-visit/access> ; for the Oxford Playhouse go to www.oxfordplayhouse.com/your-visit/access-information.

Have a good time.

Alison Heath

Study on whether adjustments in place for deaf and hard of hearing people in events and entertainment venues are adequate

This is a dissertation project by Emily Webster, a final year student at Sheffield Hallam University. Emily has both worked and been a customer of entertainment venues as a hard of hearing person and has had poor experiences that do not confirm with legal requirements. She believes that if others have had similar experiences then this shows that the legislation must change.

She would like as many people as possible to respond to the questionnaire below. If these results show a negative result she is intending to take them to a MP.

https://docs.google.com/forms/d/e/1FAIpQLSebjtc9NQCUDMVP0reucUJWNEwOeAmgty1luzuskEifBayxkQ/viewform?usp=sf_link

If you wish to contact Emily for any additional information her contact details are:
emily.webster023@gmail.com Tel.07961 522460

We Need Your Help

The NCIUA wishes to reach out to you for some help

We are interested in your views on how the Association is run and what it does:

- Do you find it helpful?
- What do you like about it?
- What do you dislike about it?
- How can we do better?
- What should be changed?

Our mission statements are listed below together with how we try to meet them:

Do you agree? If not what should be changed?

We would welcome your opinions!

Help us to help you and future CI candidates and users.

Mission Statement No 1: to offer help to everyone who might benefit from a cochlear implant
We offer support and information to all potential candidates for cochlear implantation on our website at www.nciua.org.uk Our Secretary can be contacted for more specific enquiries at secretary@nciua.org.uk. We have a booklet which gives users own stories of their life transforming Experiences and there are more examples on our website (see User Experiences at www.nciua.org.uk).

Mission Statement No 2: to campaign for them to have the opportunity to do so;
In collaboration with other professional organisations, we recently made a submission to

NICE to recommend a relaxation of the current candidacy criteria for cochlear implantation which we regard as too conservative. This was part of a consultation by NICE and we hope that it will lead to more appropriate criteria to enable many more people to benefit from cochlear implantation. (see Latest News at www.nciua.org.uk).

Mission Statement No 3: to represent the ongoing interests of cochlear implant users.
We hold meetings so that candidates, users and their families can hear presentations from professionals on the latest news and developments in the world of cochlear implants. There is also an opportunity to meet manufacturer representatives and find out about their latest products (see Events at www.nciua.org.uk)

We aim to work closely with a network of local support groups across the country at which users can meet socially and discuss their life styles, share experiences and tips for gaining the most from their cochlear implants (see Regional Groups at www.nciua.org.uk)

Please send your ideas to help@nciua.org.uk or write to NCIUA, 11 Hamilton Close, Bicester, Oxfordshire, OX26 2HX

Thank you

TOTAL NUMBER OF NEW CI RECIPIENTS IN THE UK 2016-2017

According to figures collected by the British Cochlear Implant Group 940 adults received cochlear implants in the year ending 31st March 2017. Of these eighteen were simultaneous bilateral CIs while two were bilateral sequential CIs.

Four hundred and eighty five children received cochlear implant during this period. 360 were bilateral simultaneous CIs and 39 were bilateral sequential CIs while 86 were unilateral CIs.

The total maintained population of CI users in the UK during this year were 16200 – 10417 adult CI users and 5783 children. Only six hundred and eighty two adults have bilateral CIs.

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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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