



House of Commons Debate on Cochlear Implants

On 24th March Jim Fitzpatrick, Chair of the All Party Group on Deafness, secured an adjournment debate on the funding and assessment of cochlear implantation.

A petition calling for the review of the tests approved by the National Institute for Health and Care Excellence (NICE) by Lamina Lloyd and Diane Matthews, who had both fallen foul of the Bamford-Kowal-Bench test – BKB test, was presented. They want the test reviewed and changed.

Jim Fitzpatrick referred to his briefing for the debate about the cost effectiveness of cochlear implants and better health our comes for users by Action for Hearing Loss, the Action Group for Adult Cochlear Implants, Professor Chris Raine and the Ear Foundation. He said the UK currently has one of the most restrictive tests across Europe. In this country it is not until hearing loss is over 90 dB that people qualify while in Europe the majority of clinics use a measure between 75-80 dB. He said, "We also use a word test, the BKB test, which is no longer fit for purpose according to a recent review by experts in the field who concluded 'use of this measure ... alone to assess hearing function has become inappropriate as the assessment is not suitable for the diverse range of implant candidates today.'" The guidelines were produced in 2009 but have not been reviewed since 2011. David Mowat, Under-Secretary of State for



Health, responded very positively saying "that NICE is currently reviewing the guidance and the review is likely to be completed in the summer of 2017." He was particularly encouraging about the criticism of the Clinical Commissioning Groups (CCG) and their failure to take note of the Action Plan on Hearing Loss published by the Department of Health. "On GP awareness ... if we look at the figures for children and adults, we see that there may be a reluctance to commission the technology for older people just because it's not seen as one of the natural things to do if someone lost their hearing in their 70s or 80s ... We will make sure that the fact that cochlear implants can make a radical difference to people's lives is emphasised with GPs as part of the process. In any event, when the new NICE guidance

DIARY DATES

3rd June 2017 Summer Meeting and AGM will be held at the University of London (Birkbeck Main Building), Torrington Square, London WC1E 7HX
11th November 2017 Technology Day will be held at a venue in or near Oxford. Venue still to be arranged.
Watch our website for more up to date information: www.nciua.org.uk

comes out, particularly the technical guidance, which is compulsory, that is likely to create a lot of impetus for getting the knowledge out to the CCGs and specialist centres, and therefore to people who have to make decisions.

The whole of the proceedings can be found here:

<https://hansard.parliament.uk/Commons/2017-03-24/debates/0154C58F-7CC8-4D67-92E0-D7873386BFCC/CochlearImplantation>

The pressure now will be on to see that the review is followed up by NICE. Richard Byrnes represents NCIUA on the Action Group on Adult Cochlear Implants.

The NCIUA meets at Gloucester

Although the Association's main annual event is held in London we are conscious that a majority of our members live outside the M25, and try to hold the occasional less formal meeting away from London. In 2016 this policy took us to Gloucester on Saturday 5th November, where we were able to offer local members a Technology Day event arranged by our friends at the Ear Foundation. We were able to use the facilities of the Gloucester Deaf Association on the outskirts of the City at Barnwood, working alongside the local CI user group.

We were very pleased to host an audience of just over 30, including several local people who were currently being assessed for an implant. Cath Hopkins welcomed everyone on behalf of the local group, after which our Treasurer Paul Tomlinson explained that Nigel Williams was unable to attend the event, and then proceeded to introduce the speakers in his place. Advanced Bionics, Cochlear, Med-El, and Oticon all provided updates on their current product range, and highlighted the ways in which various accessories and assistive devices could be used to enhance the benefit users get from their implants. This was Oticon's first appearance at an NCIUA event:



historically they have primarily been a hearing aid manufacturer, but are now re-invigorating the range of CIs previously marketed by Neurelec. We look forward to seeing them at our 2017 Annual Conference!

After a buffet lunch members were able to seek advice from individual manufacturer's staff and try for themselves some of the assistive devices before heading home for their local fireworks displays. We are very grateful to the manufacturer's staff for their participation, to the Ear Foundation for facilitating the event, and to the local CI user group for supporting it so enthusiastically.

Paul Tomlinson

The American Cochlear Implant Alliance

The American Cochlear Implant 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. ACI Alliance members are clinicians, scientists, educators, and others on cochlear implant teams as well as parent and consumer advocates. An annual meeting for professional members is convened.

Background

In 2010, a group of surgeons, audiologists, speech-language pathologists, and representatives of Cochlear Implant manufacturers met to discuss the initiation of an organization that would address the existing challenges they faced involving Cochlear Implants. This group determined that an inclusive and collaborative organization was needed to eliminate barriers to cochlear implantation. The organization would drive change by improving access to, and increasing awareness about Cochlear Implants through a concerted effort among health care professionals, patients and their families, corporations, clinics and hospitals. Hence the "American Cochlear Implant (ACI) Alliance Foundation" was born, and its



founding members began working on building this important organization.

The Alliance's website www.acalliance.org is well worth a visit.

Manufacturer's News

From Advanced Bionics



Advanced Bionics

Introducing the New HiRes™ Ultra Cochlear Implant

The HiRes™ Ultra cochlear implant provides the proven benefits of the Advanced Bionics HiResolution™ Bionic Ear System, featuring the thinnest implant profile from AB.

Advanced Bionics (AB) recently introduced the new HiRes™ Ultra cochlear implant. Built on proven HiRes electronics technology, the new HiRes Ultra implant features the thinnest implant profile from AB and includes the HiFocus™ Mid-Scala electrode, designed to protect the delicate structures of the cochlea.

Developed with leading cochlear implant surgeons, the HiRes Ultra with the HiFocus Mid-Scala electrode offers several high-performance features designed to suit individual patient anatomy and surgical preferences for the best possible hearing outcomes.

"AB's HiRes technology offers the fastest stimulation rate, the widest input dynamic range and the precise stimulation of the hearing nerve via 120 bands, which leads to greater music appreciation and more natural sound for recipients," says Hansjürg Emch,

President of Advanced Bionics and Group Vice President Medical of Sonova.

The HiRes Ultra is the latest generation of HiRes implants and features a low profile, which makes it ideal for recipients of all ages. The implant exceeds the industry standard for impact resistance and can undergo 1.5T MRI scans with the magnet left in place. In cases where a 3T MRI is needed, the magnet can be easily removed.

HiRes Ultra is built on the proven upgradable HiResolution™ electronic technology that delivers greater music appreciation and more natural sound than any other system.

A cochlear implant user is able to enjoy music and perceive a natural sound when the CI accurately represents the physical parameters of music – Intensity, Time and Frequency.(1)

- **Intensity** is the energy or volume of a sound. In our environment we encounter sounds in a range of intensities, from very soft to very loud ones.

- **Frequency** represents the perception of high or low sounds, otherwise known as pitch. Better frequency resolution will result in more dynamic speech or music perception.
- **Time** is the duration of a sound. The faster the sound is transmitted (stimulation rate), the better you are able to pick up on the more subtle aspects of speech (voicing and intonation) and music (rhythm, harmony).

HiResolution™ is the technology that lets Advanced Bionics implants match these three parameters in the closest possible way to natural hearing. As a result, AB recipients are able to enjoy music and perceive all natural sounds like no other technology currently enables them to.

Capture more of the acoustic environment, so you can hear the softest and loudest sounds, as well as talkers near and far.

Capture the entire frequency spectrum in high resolution, so you can better appreciate music and hear in noisy environments.

Capture the subtle aspect of speech and music, so you can have a natural listening experience.

Additionally, the HiRes Ultra implant gives recipients access to AB's Naída CI sound processor and wireless accessories that integrate with the latest Phonak sound cleaning features. The combination of AB and Phonak technologies allows recipients to understand better in noise, connect wirelessly to a variety of media or devices, and receive streaming signals between both ears. The AB and Phonak partnership offers the only hearing aid and CI processor that are perfectly made to work together, and make hearing easy and natural for bimodal recipients.

To learn more about Advanced Bionics and the HiRes™ Ultra Cochlear Implant visit AdvancedBionics.com or email info.uk@AdvancedBionics.com

References:

(1) Levitin DJ. (2006) *This is Your Brain on Music: The Science of a Human Obsession*. Dutton/Penguin.

From Cochlear

Cochlear Celebration Day

The Cochlear Celebration Day certainly lived up to its name when hundreds of Cochlear recipients, candidates and their families joined together on 25 February for fun, friendship and finding out about the latest hearing implant technology.

In celebration of World Hearing Day and International Cochlear Implant Day, Cochlear hosted the event at London's Science Museum. Two sessions were held, with the morning for Cochlear Family members and the afternoon open to the wider Cochlear community.

Presentations focused on technology updates with the Q&A sessions being extremely popular. There was opportunity to visit the stands where Cochlear Implant (CI) and Baha recipients could meet with Cochlear

Team members and find out more. The entertainment certainly kept both children and adults amused with face painters, balloon shapers and magicians making the day a magical one.

"It was a fantastic turn out," says David, aged 70, from Wigston in Leicestershire, and one of the many Cochlear volunteers who came to the event. A CI recipient himself for the past 12 years, he was giving his firsthand experience on how to use a phone clip.

Others, like 44 year-old CI recipient Tamara from Walthamstow, wanted to "celebrate our day with other CI and future implantees". She says: "I felt it was important and that we are one big family. I don't interact with many CI people in my day to day life, working, attending the gym, dancing and being a Mum."

This was Tamara's second visit to a Cochlear Celebration Day. Her first she found a great support talking to other CI recipients and Cochlear staff, as it was just three months after she was implanted. This time she came with a fellow CI recipient who she has become good friends with since meeting at the Home Counties Cochlear Implant Group (HCCIG), and who coincidentally lived down the road.

"I enjoyed the event and felt part of a community. The presentations were good, as well as the questions that were asked. I enjoyed visiting the stand demonstrating Kanso [Cochlear's newest off-the-ear, discreet sound processor] and being able to try this attached to my implant magnet, as well as discussing possible future developments," she says.

Lisa, who travelled solo from Portsmouth deciding to give her hearing dog Inca a day off, was pleased to have met the whole Cochlear Family.

"I really enjoyed the day. It was amazing to see so much information on offer. I learned so much about ReSound hearing aids and how they work together with Cochlear CI and Baha Implants to stream sound to both devices at the same time. I met new people to share my experiences with and offered my support as a mentor," says the 41-year-old, who was given a CI in 2014.

"It was also great to meet all my known friends who I have mentored, hearing how their journeys with sound have been. It was an amazing day. I wish we could do more."



For Nathan, who left New Zealand last August to study for a Masters in Clinical Audiology at the University of Southampton, the day was a first. The 29-year-old, who wants to become an audiologist, says the event was "awesome".

He wanted to catch up with two good friends from New Zealand who were going to be there. And says he was interested to hear about the Cochlear Family network and the company's "technical and sciencey updates".

"It was nice to catch up with old friends, make new friends, and of course meet Kaci the CI koala [who was popular too with all the children who attended]. I left the celebration with some great information on Cochlear's latest mini-microphone accessory for my implant - something which I've just had the pleasure of using for the first time today in a practical session at university. Needless to say it worked as promised!"

From MED-EL

Plucky Eleanor wins MED-EL UK 2016 Music Grant

With drum rolls and trumpet calls at the ready, MED-EL is pleased to announce that the under 19s 2016 MED-EL UK Music Grant winner is... Eleanor Thompson from Brayton, Selby in North Yorkshire. This music-loving, MED-EL cochlear implant user has chosen to learn the guitar, which struck just the right chord with the judging panel.

Eight year old Eleanor has already faced great challenges in her short life: she was born prematurely, weighing a mere 11b 4 oz., and her early months were a battle for survival.

Although her hearing loss was diagnosed at an early stage, due to her fragile health Eleanor was unable to undergo cochlear implant surgery until she was 3 and half years old.

In recent years, Eleanor has enjoyed attending music workshops run by Music and the Deaf through a local charity, Lollipop. She hopes that her guitar lessons will let her spend many happy hours strumming along with her peers.

As our under 19s music grant winner Eleanor receives a musical instrument up to the value of £500, and a 30 minute lesson per week for one year, plus a £30 allowance for sheet music.



Cassandra Brown, Managing Director of MED-EL UK states: "Music appeals to people of all ages and MED-EL is proud to support music appreciation for our users both through our technology and initiatives like the Music Grants. We wish Eleanor lots of fun with her guitar."

For more information about the MED-EL UK Music grant visit www.medel.com/uk/info/.

Apply now for the 2017 MED-EL UK Music Grant!

If playing a musical instrument or improving your existing skills is in tune with your plans for 2017, and you are a MED-EL implant user, apply now for the MED-EL UK Music Grant and you could be one step closer to achieving your dream.

There are two categories of music grant based on age: under 19; and 19s and over. The winners will each receive a musical instrument of their choice up to the value of £500, and one 30 minute lesson per week for a year. (All tuition fees will be paid directly to the music tutor). There is also a £30 allowance for sheet music.

So if you want to orchestrate a more musical future, make sure you submit your application before the deadline of 29th July 2017.

For more information, terms and conditions, and an online application form visit: www.medel.com/uk/info, alternatively please email conferences@medel.co.uk for a paper application form.

As long as you're a MED-EL hearing implant user and live in the UK we'd love to hear from you, so apply now and tell us why music is important to you.

Good luck everyone!

RECENT CHANGES AT THE EAR FOUNDATION

The Ear Foundation has a new Chief Executive Mel Gregory a speech and language therapist audiologist. She previously worked at the Ida Institute in Denmark. She says, 'I am privileged to have joined an organisation which makes a difference in the lives of children and adults with a hearing loss and to families through our educational and family programmes.'

Mel takes over from Sue Archbold who was Chief Executive from 2009 to 2016. During her term in office Sue built up the organisation to create the large and flourishing charity that it is today. She was a great friend of deafened adults and was largely responsible for organising the four conferences at Westminster to highlight the inadequate services available to them, in particular cochlear implantation.

Local and Regional Groups (recent changes and additions)

Sheffield Cochlear Implant Users Group (SCIUG)

We formed this new group under the umbrella of Sheffield Central Deaf Club, Victoria Hall, 2nd Floor, 41 Chapel Walk, Sheffield S1 2JB. We are a new informal social and support group. Come along a meet other cochlear implant users and prospective candidates in a relaxed atmosphere and enjoy a cup of coffee, tea, biscuits and cake (free of charge). Easy access by bus and tram and the railway station is close by.

Forthcoming meetings are on: 20th May, 17th June, 15th July, 12th August, 9th September, 7th October, 4th November, 2nd December 2017

Peter Ford, Chair and Trustee of SCDC

Email: secretarysciug@gmail.com; SMS 07802 779414

CI Five Counties (UK)

Building on the success of CI socials that have already taken place in Berkshire this group aims to support and help CI candidates and users in the five counties of Oxfordshire, Berkshire, Bedfordshire, Hertfordshire and Buckinghamshire.

The group provides opportunities for:

- Online chat with other like-minded individuals who are either CI candidates or users. It is a closed Facebook group. There are a lot of experienced members and there is also online support to tap into.
- Get-togethers so people can attend and meet each other face to face at different locations and venues across the patch.

For more information contact Anne Ryan by email: CIFivecounties@gmail.com or join the Facebook group: CI Five Counties.

CI Berkshire has outgrown its venue so the social has been spread out into smaller groups in different areas. CI Berkshire is now closed and will join CI Five Counties (UK)

Oxford Cochlear Implant Support Group (OCIS)

The contact for this new group is: Michele Motteux, 6 Desborough Close, Manor Park, Newbury, Berkshire RG14 2RN Email: michelemotteux@hotmail.co.uk

For more information about regional and local groups around the country please see our website: www.nciua.org.uk/about-us/regional-groups/ and for forthcoming events see www.nciua.org.uk/about-us/regional-events.

Fourth Conference on Hearing Loss in Adults on 12th October 2016 at Westminster Central Hall

The report 'Improving access to cochlear implantation: change lives and save money' by Brian Lamb OBE, Sue Archbold and Ciaran O'Neill was launched by Lilian Greenwood MP, Lidia Best of the National Association of Deafened People, Nigel Williams of the National Cochlear Implant Users Association and Professor Adrian Davis. The full report can be seen on the Ear Foundation's website:
www.earfoundation.org.uk/research/current-research/adult-strategy-reports/

Naked Scientist

At Cambridge University's Institute of Continuing Education there is a team of scientists, doctors and communicators whose passion is to help the general public understand and engage with the world of science, technology and medicine. This programme enabled them to introduce a wide range of subjects.

One of the episodes was about using cochlear implants to treat deafness. Mel Jewett, our ambassador, took part. She said when she first had her implant it was like listening to an electric guitar rather than an acoustic guitar. Gradually voices became more natural sounding and sounded as they always had.

David Williamson

We were saddened to learn of the death of David Williamson in November last year.

David was a member of the Executive Committee from its inception until he was forced to resign due to ill health. He suffered from Usher's Syndrome and losing his peripheral vision he qualified for bilateral implants. He was our first webmaster and a stalwart supporter of the Association attending all its meetings. He had amazing resilience and a determination to lead a full life despite his handicaps. He died peacefully at home. Thanks to his bi-lateral cochlear implants he was able to hear until the end.



Hearing Link

“
The Hearing Link Helpdesk was extremely easy to contact and gave lots of essential information & support over the phone.
”

Shona Hudson, Helpdesk Enquirer

We understand that hearing loss affects far more than your ability to hear. Our Helpdesk can provide the information that suits your individual needs and those of your family & friends.

Email, call or SMS today with your questions:
Email: helpdesk@hearinglink.org
Tel: 0300 111 1113
SMS: 07526 123255

Hearing Link is a UK charity active in England, Scotland, Wales and Northern Ireland for people with hearing loss, their family and friends.
Registered Office: 200 The Phoenix Road, Bicester, Oxfordshire, OX26 2HX. Reg Charity No. 233 898. Scottish Charity No. SC217549

www.hearinglink.org

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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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