

## BMA Patient Information Awards 2017

We were delighted when we heard that our booklet "*So what's it like having a cochlear implant: the experiences of adults*" had been highly commended in this competition which is run by the British Medical Association.

The judge commented, 'I am very impressed by this resource which provides a wealth of information from the users' perspective which is so often missing from consultations with professionals especially around hearing impairment. Produced by a user-led organisation, it uses its members in every aspect of the production; they talk about the empowerment they have experienced as a way to empower others to make difficult decisions. It acknowledges the impact that deafness has on, not only the deaf person, but also their quality of life and relationships and brings to life the effect that the procedure has on all aspects of their lives. The stories illustrate lots of different situations and will resonate differently with different people.'



Nigel Williams, Tricia Kemp and Alison Heath were very pleased to be invited to attend the award ceremony on 18th September at the BMA House. It was very impressive and attended by at least a hundred people for the presentation of special awards from the shortlist of highly commended resources which included publications from NHS Trusts and some major voluntary organisations. Although our booklet did not win an award we did get a certificate and felt honoured that it had made its mark in such a large national competition.

### DIARY DATES

11th November 2017 Oxford Technology Day at Millennium Village Hall, Straight Mile Road, Horton-cum-Studley OX33 1AD. Please contact Dr Ray Glover (email: [secretary@nciua.org.uk](mailto:secretary@nciua.org.uk)) to book a place.

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

# Candidacy for Cochlear Implants: who could benefit in future?

Summary of a presentation by Pádraig Kitterick, Associate Professor in Hearing Sciences, Nottingham Biomedical Research Centre at the NCIUA Summer Meeting 2017

Why should a candidacy criteria be set? The advantages of doing this are to help maximise health gain and therefore the cost effectiveness of cochlear implantation and to help ensure equitable access to the intervention. The disadvantages are: it is difficult to determine what factors should be taken into account; it needs to apply to a broad a population as possible; and it would be inflexible.

Various methods for developing the criteria have been considered but all present problems. The UK Cochlear Implant Study Group (UKCISG) found that the outcomes from unilateral cochlear implants in postlingually deafened adults are variable and difficult to predict precisely from data gathered before surgery. The object was to derive and validate a method for specifying criteria of candidacy that take this variability into account.

The NICE Technology Appraisal Guidance 166: Cochlear implants for children and adults with severe to profound deafness is problematic because it is heavily based on the UKCISG study which was published in 2004 and the data is from adults receiving cochlear implants between 1988 and 2000. The adults had very poor hearing (>115 dB hearing loss in the better ear) and there was no data for children.

Introducing the guidelines did have an effect. Patients implanted under these guidelines were likely to have better hearing function (speech perception), a larger and healthier population of nerve cells in the inner ear and greater access to hearing in the non-implanted ear. The problem is that the proportion of hearing aid users with cochlear implants has gone up.

The British Cochlear Implant Group agreed that the need to review the guidelines is a priority. This is because those working in the CI field in the UK believe that the guidelines for candidacy no longer reflect the entire population of patients that the BCIG and the UK implant field consider to be potential CI candidates. There were various ways forward but consultation with patients and clinicians to identify potentially appropriate indications for a cochlear implantation was thought the best one.



Appropriate procedure was defined as 'the one in which expected health benefit exceeds the expected negative consequences by a sufficiently wide margin that the procedure is worth doing, exclusive of cost.'

The result of the consultations were the following:

## **Recommended Criteria 1**

Unilateral implantation in children and adults is generally appropriate when:

- the ear to be implanted has >90 dB hearing loss regardless of the degree of hearing loss in the other ear. Implantation in profound deafness is a per ear decision.
- The ear to be implanted has between 80-90 dB hearing loss and if the other ear also has a >80 dB hearing loss. Implantation in the severe ear requires the other ear to be at least as severe.

## **Recommended Criteria 2**

Providing a second implant for those who already have one is generally appropriate if the ear to be implanted has a >80 dB hearing loss.

Bi-lateral implantation is generally appropriate in children with a hearing loss of >80 dB in both ears and in adults with a hearing loss of >90 dB in both ears.

### Consensus statement

- A.** Expanding candidacy to those with less profound forms of hearing loss would be appropriate.
- B.** The BKB sentence test does not adequately assess the difficulties with listening that adults and children experience in everyday life.
- C.** The process to determine whether someone receives sufficient benefit from their hearing aid should be revised to better assess real world listening difficulties.
- D.** Assessment procedures should be based on evidence that they are reliable and valid for determining candidacy for cochlear implants. Different procedures may therefore need to be adopted for different sub-groups of patients who are potential candidates.
- E.** Cochlear implantation is not only appropriate where the primary motivation for treatment is the

restoration of speech understanding but it can also be appropriate where it is for the alleviation of tinnitus.

### From present to future

- The results of the consultation and consensus statement should be disseminated as widely as possible and a summary of the consensus process and results presented to NICE.
- The implications of expanding the candidacy should be considered
  - Is there capacity in the cochlear implant service?
  - Would it lead to prioritisation/rationing?
  - How can we assess 'real world' listening difficulties reliably?
- Further research should be conducted to gather evidence of the effectiveness and cost effectiveness of cochlear implantation.

## Diane Matthews

Diane's petition to get a review of the NICE guidelines on cochlear implants helped to secure the adjournment debate on cochlear implantation in the House of Commons in March this year. Although Diane is severely deaf she did not pass the Bamford-Kowat-Bench test (BKB sentence test) which, it is generally agreed, does not adequately assess listening difficulties in everyday life. However, earlier the year it was found that Diane's hearing had deteriorated to the point that it met the criteria for an implant. When we last heard from her she had had her cochlear implant from Cochlear at Manchester and was awaiting switch on. We wish her all the best.

Diane's petition now has 1007 signatures but we have been informed that there will be some delay before the TA166 cochlear implants will be reviewed. This is because NICE have received a significant amount of information since it was published and have decided to conduct a more in-depth review. They are in the process of analysing the evidence and hope to go out to consultation in due course.



***Diane at the NCIUA Summer Meeting***

# Manufacturer's News

From Advanced Bionics

**Advanced Bionics extends their portfolio of solutions for CI users with the introduction of the Naída Link CROS Solution**

The advertisement features the Advanced Bionics logo (AB) and the text "Advanced Bionics". The main headline is "The Simple Way to Hear More". Below this, it says "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?". At the bottom left, it says "A Sonova brand" and at the bottom right, it says "Rachel P., Naída CI AB Recipient". On the right side of the advertisement is a photograph of a smiling woman with shoulder-length brown hair, wearing a dark blue and white striped sweater.

Hearing your best is important and you shouldn't settle for anything less than a complete solution. This means that you want to keep both of your ears working together and contributing to your hearing experience.

**The Naída CI sound processor is the only cochlear implant system capable of automatically establishing a wireless network with the hearing device on your other ear**, using Phonak Binaural Voicestream Technology™.

This network allows you to simultaneously adjust your volume or change programs in both ears with a single button press, keeping you perfectly synchronised. The devices can share audio signals, allowing you to stream phone calls to both ears and enjoy better speech understanding in really noisy backgrounds.

The Naída CI can communicate with another Naída CI, a hearing aid, or even a wireless CROS microphone worn on the other ear. **With the right combination, you are sure to enjoy the sounds from both ears**, no matter where you are on your hearing journey. The Naída CI sound processor can meet your personal hearing needs. If you have hearing in your other ear or even if you don't, there is a Naída solution for you.

## From Cochlear

### Hear Your Way with Nucleus® 7!

Some of you will have already seen on social media the announcement that Nucleus® 7 is now available. With Nucleus 7 comes an exciting new approach to managing your hearing. We call it HearYourWay. Here's a quick summary of what's new!

#### **WEAR YOUR WAY**

The Nucleus 7 Sound Processor is smaller and lighter than ever, so it's super comfortable for even the smallest ears. But, with the new chip technology inside, it also boasts 50% longer battery life!

Of course, there's still the ever-popular Nucleus Kanso® if you prefer an off-the-ear processor. Now there's even more opportunity to personalise your sound processor, whether it's with different colours, retention options or Aqua+ to make your sound processor waterproof.

### **HEAR YOUR WAY**

Nucleus 7 and Nucleus Kanso Sound Processors both feature the most advanced sound management system available. Wherever you go, the sound processor automatically adjusts to your environment so you're confident of hearing your best. If you have natural hearing, Nucleus 7 is Hybrid ready to help you make the most of it for the best hearing in every situation.



### **CONNECT YOUR WAY**

Connecting with people is what life is all about and exclusive technology makes this easier than ever with Nucleus 7. This is the world's first cochlear implant sound processor that is Made for iPhone compatible, so you can stream directly from an iPhone, iPad or iPod Touch to your Nucleus 7 Sound Processor. If you have a cochlear implant and a compatible hearing aid, you can control and stream sound directly to both ears from your Apple device! The Nucleus Smart App allows you to adjust settings and access personalised hearing information with the Hearing Tracker or locate a missing sound processor, all using your iPhone. And, of course, Cochlear's True Wireless™ Devices are there for the most challenging listening environments.

### **CARE YOUR WAY**

With Nucleus 7, Cochlear is also introducing tools to help your clinicians. Using True Wireless technology, they can now provide wireless fittings so that you can move more freely and naturally during a fitting, without being tethered to the computer.

Why not talk to your clinic about Nucleus 7 at your next appointment

**From MED-EL**

**MED-EL**

### **Enjoy Wireless Connectivity with the Roger™ 21 for SONNET**

Enjoy wireless connectivity and benefit from optimal hearing in challenging environments with the new Roger™ 21 FM battery sleeve for the SONNET audio processor. Produced by Phonak, the Roger 21 sleeve is a fully integrated receiver, meaning there's no need for a neckloop or to fix an additional receiver to the bottom of your audio processor. This simple-to-use battery sleeve makes it easy to connect the SONNET to a range of Roger wireless devices to stream sound from a variety of sources.



The Roger 21 is ideal for use at meetings, in the classroom, for conversations in noisy settings, for talking on the telephone, or simply for enjoying listening to music at home.

This exciting new device is now available to order from retailers approved to supply Phonak products.

For more information about the SONNET and other MED-EL products, visit [www.medel.com](http://www.medel.com).

# Cochlear Implant Care: putting patients in charge

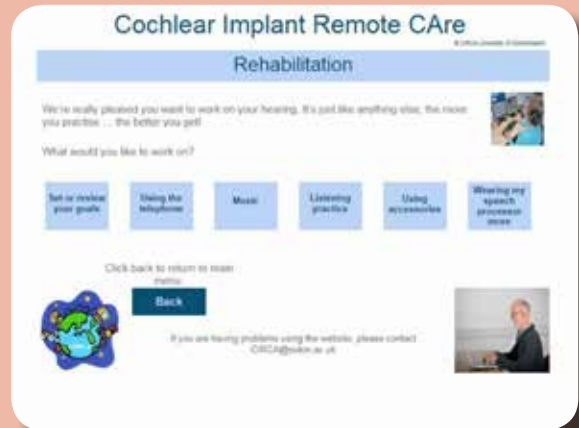
Helen Cullington, Southampton University Auditory Implant Services

Patients attached to the Southampton cochlear implant programme live mainly in the south but others are spread out all over the country and have to travel long distances for appointments. There is also a vast increase in patient numbers – currently 1,400 people with profound deafness receive an implant in the UK every year. There are nineteen CI centres which are responsible for a lifetime follow-up. The demand for cochlear implantation is expected to increase as the number of pensioners is projected to rise by 28% in twenty years and only 5% of deaf adults who could benefit from cochlear implants have them.

A few patients would like to continue in the same way with regular appointments but others find the present arrangements both time consuming and inconvenient. The current care provision is not person centred and a drain on funding. Instead of continuing with the same level of service or the same number of patients the aim is to treat more patients with a streamlined optimised service.

With this in view the Southampton programme are running a trial of remote care which includes a home hearing test, allows upgrades to be sent home and provides an online support tool. It should be noted that the Advanced Bionics Sound Success scheme already allows patients with their processors to order spare parts directly from the company or hospital by going online. It has been running for several years.

The Southampton remote care project has sixty participants – thirty who use the usual care pathway and thirty who use the remote care project. Example of three online questionnaires which allow patients to interact with the remote care programme are shown below:



There was a significant increase in patient activation in the remote care group and hearing stability got better in this group. Regarding quality of life there was no change in either group. Both patients and clinicians were keen to continue with remote care.

The next steps are for a clinical roll out in the Southampton. The introduction of a portable microphone tester is planned because microphones are often affected by humidity and dust. Other centres are very interested and it is hoped to work with them.

## Summary of presentation by Alison Heath



OXFORDSHIRE  
 HERTFORDSHIRE  
 BEDFORDSHIRE  
 LONDON  
 NORTHAMPTONSHIRE  
 BUCKINGHAMSHIRE  
 BERKSHIRE

# CI High Five (UK)

## Support Group

This is a **voluntary** group originally setup in January 2017 to support cochlear implant (CI) users and candidates across Oxfordshire, Hertfordshire, Bedfordshire, Buckinghamshire, Berkshire and Northamptonshire. The group has grown rapidly and currently has nearly 200 members online and growing by the day! We have recently expanded and now offer support to those who may need it in the London area too. **How?**

**Facebook Group (Closed)** - You'll meet like-minded people online who are progressing on the CI journey or who already wear a cochlear implant. You may be a new candidate and have no idea where to turn to for support? You can be assured this group is here to help **YOU** on your CI journey! There is a lot of experience online from those who are travelling or have travelled the CI journey. It's amazing what you can learn from others and how much support is available to you. Queries, concerns or just general chat. On Facebook search for: CI High Five (UK)

**Social Gatherings** - Since January 2017, the group has held CI socials in Aylesbury, High Wycombe, Milton Keynes, Reading and Oxford. The events have been amazing and very successful in

providing the opportunity to meet face to face and chat. People find much inspiration from attending the socials and meeting others. The socials are **VERY** well attended and dates are in place for the remainder of the year and into 2018 where we shall continue to host events in Oxford, Reading, St. Albans, Milton Keynes and London.

So, why not come along? Our next CI social is as follows:

**Saturday, 4th November 2017**  
**INNS 1888 MARYLEBONE**  
**21 Devonshire Street**  
**London. W1G 6PD**

**Between 12 noon and 3.00 pm**

The CI socials are informal and friendly with people that understand about hearing loss and the challenges it presents because we have been there ourselves! No need to worry or be stressed about struggling to hear as the venue will have no background noise (music) to aid better hearing for those who may be at the start of the journey or new to the CI hearing world! Whatever stage of the process, people will understand and be supportive.

Partners, parents of CI children and friends of CI users or candidates are also invited as well as Hearing Dogs. We welcome people with a wide variety of backgrounds too – whether you are born deaf, late deafened, sign, don't sign or a bit of both. This friendly and supportive group is for all brands of cochlear implants, Advanced Bionics, Cochlear and Med-El.

If you are interested in attending an event all we ask is to let us know you are coming via email: [CIHighFive@gmail.com](mailto:CIHighFive@gmail.com)  
 Get in touch!



*A recent gathering in Oxford*

*Continued on next page*

## Hearing Link and Hearing Dogs for Deaf People Merger

Hearing Link has merged with Hearing Dogs for Deaf People following the public announcement on 18th July 2017 at the Hearing Dogs AGM, attended by their joint Royal Patron, HRH The Princess Royal. The merger formally took place on 1st August 2017.

In common with many small charities fundraising has proved extremely difficult for Hearing Link. By merging with Hearing Dogs, and incorporating Hearing Link as a distinct service within the larger charity, the future of Hearing Link's work has been secured and they can plan to deliver their life-changing services to ever increasing numbers of people.

Hearing Link's name will not change, and their vision remains a world where everyone can enjoy life and participate fully and confidently, whatever their level of hearing. Hearing Link's services will continue to run as before, but with the stability of a much larger charity to strengthen their work. They look forward to continuing 'business as usual', retaining their identity, logo and UK-wide offices, and working with our volunteers and staff to provide their usual Helpdesk, specialist programmes and services, website and social media platforms.

The merger between Hearing Link and Hearing Dogs and Hearing Link brings three key benefits:

- **Impact** – They will be able to provide more life-changing services to a greater number of people than ever before.
- **Integration** – The merger will enable the two organisations to integrate services, and the recipients of hearing dogs will benefit from access to Hearing Link's broad range of helpful advice and support, rehabilitation programmes and practical solutions.
- **Efficiencies** – The collaboration will provide logical cost benefits by efficiently combining back-office functions, such as

finance and administration, to ensure donated funds are used in pursuing our core purpose as much as possible, and providing the stability to secure future services.

Guided by their UK network of experienced, knowledgeable and passionate volunteers, Hearing Link will continue to support people with hearing loss, their family and their friends as they adjust to and overcome their emotional and practical challenges, helping them find better ways to manage their hearing with confidence. Lorraine Gailey, Chief Executive of Hearing Link, says: "Our values and aims are so closely aligned, it was a natural move for us to come together to create a stable future for Hearing Link, where we can reach even more people and their families, offering even better support for as long as they need us."

The merger of the two organisations has ensured the future of Hearing Link. It means that the wealth of knowledge and expertise within the charity will not be lost, and will now be greatly enhanced through the development opportunities provided by over 100 combined years of experience in helping people with hearing loss.

For more information please download Hearing Link & Hearing Dogs Merger FAQs – July 2017.

### National Cochlear Implant Users

|                           |   |
|---------------------------|---|
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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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### CI High Five (UK) Continued

And finally ... if you are wondering who we are. Yasir, Anne and Carol are profoundly deaf individuals who have been through the CI journey and implanted. Our lives have completely changed as a result of the implant and we now enjoy being part of the hearing world. Helping others is a small token of appreciation for the fabulous gift of hearing we have been given. **YOU** could be the same! Join the Facebook Group and Come Along to our first CI social in London. It will change your life for sure!

Yasir

Anne

Carol