

## Advocacy

It is a disturbing yet researched fact that only 5 % of adults who have severe to profound deafness and hearing loss actually get a cochlear implant (CI) in spite of the benefits to the individual and society being well proven, including its cost effectiveness. Whilst strict eligibility criteria in the UK and resource provision are partial causes of this situation, by far the biggest factor is the simple fact of lack of awareness of CIs and its life transforming results. Advocacy, by raising the profile of CIs through publicity and education of all the professionals concerned, is the only motivator that will address this lamentable state of affairs.

A new initiative in this is the formation of the Cochlear Implant International Community of Action (CIICA). It's not an organisation but a community, a network. It has formed following an international consultation with key stakeholders about the role of CI advocacy work and its strengths and challenges. CIICA provides an opportunity for a new way of working for CI advocacy groups, bringing them together with opportunities for sharing and collaboration to strengthen the user, including children and young people, and family voice. The vision of CIICA is a world in which awareness of the benefits of CIs are well known to those with deafness and hearing loss, their families, professionals in the field of deafness and hearing loss, the general public and public health decision makers. A world where access to CIs and lifelong support is available for all appropriate.

The goals for CIICA are to increase the number of people globally who have access to cochlear implants and lifelong aftercare by:



*Sue Archbold*

- Raising the international global awareness of the health, social and economic benefits of cochlear implants for those who could benefit from implantation, health care practitioners and wider society.
- Empowering user led advocacy and awareness raising activity to influence governments and health funders to invest in addressing the under provision of CIs and other implantable technologies, related habilitation, after care and up-grades.
- Supporting CI advocates with the tools they need to achieve change.

### **BRITISH COCHLEAR IMPLANT GROUP**

The BCIG have just published their spring newsletter. This can be seen at:  
<https://www.bcig.org.uk/newsletter-spring-2021/>

Network Members will include voluntary organisations and groups and individuals involved in advocacy work, patient, family and industry advocacy groups and individuals, professional organisations involved in CI and hearing loss, policy groups and institutions related to hearing loss, Academic institutions with links to policy work, International agencies with an interest in hearing loss and Governments and funding decision makers.

The NCIUA has joined CIAG as a founder member and looks forward to helping improve awareness of cochlear implants and the benefits that this life transforming procedure can bring. Full details of CIAG can be seen on its website at [www.ciicanet.org](http://www.ciicanet.org)

Sue Archbold is Co-ordinator and Brian Lamb is Public Policy Advisor.

## Integrated Care Systems

Following much press and media coverage readers may be aware that NHS England is undergoing another organisational change. This will be the third major change in its structure over the past 20 years and one which, potentially, will resolve long standing issues on health and care provision.

This plan which began quietly several years ago is the formation of Integrated Care Systems (ICS) in which both the medical care and the social care provided by local authorities are integrated to provide a comprehensive platform to population groups of around 1 million people. In an integrated care system, NHS organisations, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve. This enables health and care organisations to join forces and apply their collective strength to addressing their residents' biggest health challenges, many exacerbated by Covid-19. In this reorganisation the existing 135 Clinical Commissioning Groups (CCGs) will be disbanded with senior staff repurposed into ICSs whilst Public Health England will also be disbanded.

By December 2020 there were 29 ICSs covering more than 35 million people in England; ICSs will cover the whole of England by April 2021, with 13 remaining parts of the country working to achieve designation. The NHS England has since announced it is seeking views on proposals to strengthen ICSs, including its recommendations to the Government for putting them on a statutory footing in 2022. Such legislation would give a legal basis for the integration of health and social care

The Hearing Loss and Deafness Alliance (HLDA)

responded to the initial consultation on Integrated Care. Its main aim was to raise points about equality of access and the profile of hearing loss; also, to question the resources available on hearing loss to assist commissioners and the importance of the Governments and NHS Action Plan on Hearing Loss. HLDA is a group of 32 organisations spanning the voluntary and independent sectors and professionals. The NCIUA is a member of the Alliance which seeks to represent the needs of children, young people and adults with hearing loss, deafness and tinnitus on issues related to audiology, hearing services and public health.

Led by Professor Brian Lamb, the Alliance has been assured by NHS England that it plans

to hold a separate public consultation on a new procurement regime in addition to this current consultation to address stakeholder concerns about governance,



**Brian Lamb**

accountability, transparency and efficiency, and how patients' rights will be protected in the new system. The Alliance's main concern is that for too long NHS commissioners have incorrectly ranked hearing care as a low priority service. This has come at a significant cost to patients, their friends, family and carers and the health and care system. Brian has urged the Department

of Health and Social Care (DHSC) to build protections into planned new legislation to prevent this happening again.

Addressing this risk is now an urgent public health priority because 12 million people in England have hearing loss, yet only 1/3 currently

have help owing to the low priority afforded unsupported hearing loss and longstanding inequalities in access. This is best done by building in protections for patients who require hearing care, including access to a choice of provider and a comprehensive care pathway as set out in NHS and NICE guidelines.

## Manufacturer's News

### From Advanced Bionics

#### Introducing the NEW Marvel Cochlear Implant Platform from Advanced Bionics

Now, it is time for Advanced Bionics to unveil our latest cochlear implant sound processor platform Marvel, featuring the Naída™ CI M sound processor for adults and the Sky CI™ M sound processor, the world's first paediatric cochlear implant solution.

For over 25 years, Advanced Bionics has been the cochlear implant innovation leader. Now, in close collaboration with Phonak, the global leader in hearing care, we are thrilled to bring the highly successful Marvel hearing aid technology to our Advanced Bionics cochlear implant recipients and families.

#### Welcome to Naída CI M: Connect with the Moments You Love

Naída CI M offers a **powerful hearing experience** with effortless **comfort and convenience**. AutoSense OS™ 3.0 operating system gives you automatic access to a variety of features which **customise sound based on your environment**. This means you're hearing your best every moment, every day, no matter where life takes you.

Unlike any other cochlear implant platform, Naída CI M can **stream calls and audio directly** from virtually every smartphone and Bluetooth®-enabled device. Roger™ technology boosts your hearing performance in challenging listening situations, without extra devices attached to the sound processor.

The unique design of the battery at the bottom of the sound processor curves against the contour of the ear, keeping the device **secure and conveniently tucked away** while the all-new, **slim headpiece** stays out of the way.

Our **waterproof battery** gives you the same great hearing while you enjoy even the most rugged

activities, all while providing secure, worry-free wearing.

And our **AB Remote app** provides discreet and convenient management of all your hearing devices on your smartphone.

If you use a cochlear implant and a hearing aid, you can have a **Naída CI M** on one ear and a **Phonak Naída™ Link M** hearing aid on the other. This customised approach is designed to ensure both devices will process sounds in the same way. Together, they provide consistent sound experiences and excellent speech understanding, unlike having a hearing aid and a cochlear implant that are not designed to work together.

#### Welcome to Sky CI M: Connect with the Moments You Love

Help your child connect to their world with Sky CI™ M sound processor, the world's first cochlear implant solution designed specifically for children. AutoSense Sky OS™ 3.0 operating system is **uniquely designed with typical children's listening** situations in mind, adjusting and optimising your child's sound processor automatically wherever they go.

Taking advantage of the established Phonak Marvel technology, Sky CI M provides **excellent sound quality and consistent access to the sounds** in your child's environment, so they can always be a part of the conversation.

The Roger™ technology and Bluetooth® connectivity allows for **streaming all day with no extra accessories** for your child to wear on the sound processor, so the focus is on the teacher's voice at school or their favourite music playlist at home.

Sky CI M comes in a variety of stylish, child-preferred colours. The M Waterproof Battery and Slim HP AquaMic™ headpiece are swim class and bathtub ready, so your child doesn't have to miss out on any fun or learning.

AB knows little ears. That's why Sky CI M comes with a variety of wearing options that can be customised to the changing needs of your growing child.

The AB Remote app gives you convenient control and management of your child's hearing devices, until they're ready to do it on their own.

For more information visit:

[www.advancedbionics.com](http://www.advancedbionics.com)

Or if you have any questions please email :

[info.uk@advancedbionics.com](mailto:info.uk@advancedbionics.com) or phone 01223 847

## From Cochlear



### Time to upgrade... What should I choose?

What are the differences between our latest sound processors? And what's the difference between a behind-the-ear and off-the-ear sound processor?

Behind-the-ear sound processors, such as the Cochlear™ Nucleus® 7 Sound Processor, sit behind your ear, with an ear hook to keep them in place. A cable and coil connect to the sound processor and the coil is held on the head by a magnet.

Off-the-ear sound processors, such as the Cochlear Nucleus Kanso® 2 Sound Processor, sit on the side of the head. The Nucleus Kanso 2 Sound Processor is an all-in-one device that contains the processing unit, microphones, magnet and battery.

Let's compare the features of our latest sound processors:

	<b>Nucleus® 7 Sound Processor</b> 	<b>Nucleus® Kanso® 2 Sound Processor</b> 
<b>Location</b>	Behind-the-ear	Off-the-ear
<b>Nucleus® Smart App</b>	✓	✓
<b>Compatible with Cochlear True Wireless™ devices</b>	✓	✓
<b>Smartphone compatibility*</b>	Direct streaming from compatible Apple or Android devices. Other smartphone devices streaming with Cochlear Wireless Phone Clip	Direct streaming from compatible Apple or Android devices. Other smartphone devices streaming with Cochlear Wireless Phone Clip
<b>Cochlear Aqua+**</b>	✓	✓
<b>Simple interface</b>	One-button design	Button-free design
<b>ForwardFocus†</b>	✓	✓
<b>Disposable batteries</b>	Two required	N/A
<b>Rechargeable batteries</b>	Standard and Compact options	Built-in rechargeable battery
<b>Battery Life***</b>	Up to 80 hours <sup>1</sup>	Up to 18 hours <sup>2</sup>
<b>Rechargeable battery charger</b>	✓	✓
<b>Monitor sound quality</b>	Compatible with monitor earphones	Sound Check in the Nucleus Smart App

Colour range

6 colour options

5 colour options

For more information about either sound processor please visit [cochlear.com](http://cochlear.com)

### Cochlear accelerates ground-breaking remote health services

The Cochlear Nucleus® 7 Sound Processor in combination with this amazing new feature in our Nucleus® Smart App allows you to check your hearing health from the comfort of your own home. Remote Check is a convenient, at-home testing tool that allows patients with a Cochlear Nucleus 7 or Kanso 2 Sound Processor to complete a series of hearing checks on their compatible iOS device. Results are sent via the Smart App directly to your clinic to be reviewed by your audiologist. They can then communicate back to you through the app to help you with any questions or concerns you may have. Cochlear has opened up this technology across the UK and Ireland, allowing more recipients and healthcare professionals to take advantage of these features.

If you have been having conversations with your audiologist about an upgrade Cochlear may be able to help you in partnership with your clinic. We have started to offer an Upgrade Direct to Recipient service. This enables us to ship a new processor directly to your home along with all the accessories you will need in a Cochlear backpack. We hope that by enabling a “contactless” upgrade option you can continue to gain access to Cochlear’s latest technology.

These developments are very exciting and changing the world we all live in. As we start to recover from the current situation clinics can choose to adopt these services, but this will be dependent on their capacity to do so. Your clinic will advise you as to what services they are able to offer.

### From MED-EL

Here at MED-EL we want to provide our users and caregivers access to information, resources and services in one convenient place.

Introducing the myMED-EL Portal – your personal access to everything MED-EL!

The graphic features the myMED-EL logo at the top, with the tagline 'Your personal access to everything MED-EL'. Below this, the text 'YOUR BENEFITS' is followed by three icons: a person with a speech bubble (myConnection), a person icon (myProfile), and a stack of papers (myInformation). To the right, the text 'ON ALL YOUR DEVICES' is positioned above images of a smartphone, a laptop, and a tablet. At the bottom left, there is a photo of a woman talking on a mobile phone, with a red 'REGISTER' button below it. The text 'MATCHING YOUR NEEDS' is written in large, light letters at the bottom right. A red line connects the icons and devices, forming a path around the central content.

From the myMED-EL Portal, our users and caregivers can access the myMED-EL Shop for all their accessories and spares as well as the MED-EL Academy to learn more about their devices and about MED-EL. Not only that, from 2021, you'll also have access to your very own Download Centre, which will provide you with resources on software updates and new product information wherever you are!

Registering for a myMED-EL account is easy. Simply sign-up at <https://my.medel.com/> and fill in your details. You'll receive a confirmation email within 2 working days once your details have been verified. You can then simply log in to access your bespoke portal and resources.

#### **Already a registered user of myMED-EL Shop?**

The myMED-EL Shop has joined the suite of applications on the new myMED-EL Portal. With a new design and login, it's now easier than ever to browse and shop for your favourite MED-EL spares and accessories. Simply re-register using your existing myMED-EL Shop details at: <https://my.medel.com/>

If you have any questions about the myMED-EL Portal, please email our dedicated Customer Service team at [customerservice@medel.co.uk](mailto:customerservice@medel.co.uk)

Here at MED-EL we want to provide our users and caregivers access to information, resources and services in one convenient place.

#### **First ever surgeries in Europe with a totally implantable cochlear implant (TICI)**

Thank you for your interest in our announcement of the first person in Europe to receive a totally implantable cochlear implant. It was implanted by Prof. Dr. Philippe Lefebvre, head of the ENT Department of the CHU of Liège and Professor at the University of Liège in Belgium, as part of a feasibility study on 24 September 2020.

With this implantation MED-EL sets another revolutionary milestone in its long-standing history of technological innovations, as a totally implantable cochlear implant is the most innovative and sophisticated technology in the field of hearing loss solutions. The TICI contains all the internal and (hitherto) external components of a cochlear implant system in one device placed underneath the skin, including the audio processor, microphone, and power supply. The TICI is expected to give users great hearing with even more comfort and convenience. However, it will take several years before it receives market approval and in the meantime we continue to provide severe/profoundly deaf children and adults excellent outcomes with our Synchrony 2 cochlear implant and choice of processors – the SONNET 2 behind the ear model; and the RONDO 3, our third generation single unit, off the ear audio processor, with wireless recharging. Both processors feature our advanced ASM3.0 plus FineHearing sound coding, along with a comprehensive set of connectivity options, and optional smartphone remote control.

Over the years as more milestones are achieved in advancing our TICI towards market approval and general availability, we will share news, as it becomes available. Further information on all MED-EL products and services can be found at [www.medel.com](http://www.medel.com)

## **From Oticon Medical**

**The Neuro System has a bimodal solution for all Cochlear Implant patients**  
Easy, built-in compatibility with Oticon Hearing aids



Cochlear implant systems from Oticon Medical are renowned for the sound quality and reliability they provide to users. Oticon hearing aids are built on the same foundations and can now be seamlessly used with the Neuro Cochlear Implant System to deliver a comprehensive binaural hearing solution to patients.

### **Do you feel that your hearing aids are no longer enough?**

For some people a cochlear implant on one ear and a hearing aid on the other ear could be an effective solution. This is known as a bimodal solution<sup>1</sup>. Hearing with both ears is important as it helps speech understanding in noise and lets you know where sound is coming from.

### **Can two different hearing solutions complement each other?**

The two solutions in a bimodal setup complement each other and together they may improve your overall hearing performance<sup>2,3</sup>. The cochlear implant provides clarity while the hearing aid provides loudness and sound depth.

### **The perfect match**

If you have a Neuro 2 cochlear implant, or are considering getting one, you may be able to support your hearing by combining Neuro 2 with an Oticon hearing aid on the other ear. Oticon and Oticon Medical are part of the Demant Group – one of the world's leading hearing healthcare companies. This

shared background gives you access to one of the world's strongest research and development teams. It also creates the perfect match of devices for a bimodal solution.

### **Two ways of hearing - one focus on the brain**

Oticon Medical and Oticon devices are both designed to provide clean speech with minimal distortion using the principles of BrainHearing™.

What does BrainHearing mean to you?

BrainHearing recognizes that listening and speech understanding actually take place in the brain<sup>4</sup>. That is why our cochlear implant system and hearing aids are designed with the goal in mind to support the brain's natural ways of making sense of sound.

Designed for clean speech in both ears

Even though a Neuro 2 cochlear implant and an Oticon hearing aid use different ways of transmitting sound signals to the brain, they are both designed to help you perceive speech more clearly. This can also make it easier for your brain to decode what is being said, even in noisy environments<sup>5,6,7</sup>.

### **Explore Bimodal**

To find out more about Bimodal, please visit our website:

<https://www.oticonmedical.com/cochlear-implants/solutions/bimodal>

## **Adult Cochlear Implants**

With the goal of addressing lack of awareness and improving literacy surrounding cochlear implant use in adults, an international group of clinical experts in the fields of otology, audiology, and hearing science were brought together to form a Delphi panel from which a Consensus around cochlear implant candidacy was agreed and an International Consensus Paper created. In clinical research, the key aim of a Delphi consensus is to achieve a set of statements that reflect current clinical expert thinking in the field. This is the first time that experts from different countries and several continents have come together in order to create a document that reflects the status of cochlear implantation for adult recipients.

Conservative industry estimates suggest that no more than 1 in 20 of adults who could benefit from a cochlear implant actually get one. Such under-

provision leads to a substantial unnecessary burden to the individual with hearing loss, leading to a poorer quality of life; it may also have economic and social consequences.

There are many reasons contributing to this under-provision, including low awareness of the benefits of cochlear implants among healthcare professionals and individuals with sudden sensorineural hearing loss (SNHL), as well as a lack of specific referral pathways.



**Gerry O'Donoghue**

International guidelines on adult cochlear implant candidacy are limited, and country-specific guidelines are varied, leading to disparate levels of access and systemic underutilization across the world. Without standard clinical guidelines, individuals who can benefit from a cochlear implant may not receive one.

The scope of this consensus study was to develop consensus statements specifically related to the Relationship between hearing loss and depression, cognition and dementia use of unilateral CI for the treatment of bilateral severe, profound, or moderate sloping to profound SNHL in adults. However, further research to develop consensus statements on the use of bilateral CI in adults, unilateral and bilateral CI in children, combined electric-acoustic stimulation in children and adults and unilateral implantation for single-sided deafness and asymmetrical hearing loss in adults and children will also be important for optimising hearing and Quality of Life (QoL) outcomes for patients.

Professor Gerard O' Donoghue, steering committee member of the Consensus Delphi Process and Professor of Otology and Neurotology at the University of Nottingham stated, "We need everybody's opinion, we need everybody's help in mobilising support, to drive forward an agenda that is favourable, for hearing impaired patients, especially those for whom cochlear implantation may be appropriate; and who at the present time are denied that intervention. Globally, we all have to unite to do this work, and to make sure that the interventions for hearing impairment are more readily available, for the millions of people who at the present time are denied it".

The ultimate goal of the consensus statements is to raise awareness of cochlear implants, and improve clinical practice to provide the best possible hearing outcomes and quality of life in adults with SNHL who are eligible for a cochlear implant.

The consensus statements set out recommendations on seven key areas:

- Awareness of cochlear implants
- Best practice clinical pathway for diagnosis
- Best practice guidelines for surgery
- Clinical effectiveness of cochlear implants
- Factors associated with post implantation outcomes
- Relationship between hearing loss and depression, cognition and dementia

Cost implications of cochlear implants

Each of these recommendations can be seen in detail at [www.adultheating.com](http://www.adultheating.com)

## Home Counties Cochlear Implant Group

This active group, started and chaired by Jenny Burdge, has helped and supported many people in London and the Home Counties for over 20 years. Jenny, who is a member of the NCIUA Executive, together with her committee colleagues recently decided to wind down the group as a charity and just continue as an informal social group under the auspices of NCIUA.



**Jenny Burdge**

Their committee agreed to donate their residual funds of £12985 to the NCIUA with the proviso that it should be spent on a project that will benefit CI users and prospective CI users. We are enormously grateful for this magnificent gesture and money.

It now remains to decide how best to fulfil the conditions of this donation and all members are asked if they have any ideas as to how we could use this very generous donation to please let us know. This project will be debated at future Committee meetings together with your own welcome suggestions.

## National Cochlear Implant Users Association

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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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