Newsletter NCIU

NATIONAL COCHLEAR IMPLANT USERS **ASSOCIATION NEWSLETTER**



Summer Meeting 2014

This was a small but very enjoyable and friendly meeting with the audience participating in the various sessions. We were especially pleased to have our new President, Jackie Ashley with us.

The first two speakers – Tracey Twomey from Nottingham and Sandra Driver, Speech and Language Therapist from St Thomas', London – spoke about the adult cochlear implant teams today and how they operate. As their workloads have increased with no corresponding increase in staff they have had to look at ways and means of operating more efficiently without affecting their high standards of patient care.

One way of saving staff time is to avoid patients having to make appointments for routine maintenance of their devices. Arrangements are often made with the manufacturers for spares and broken parts to be replaced directly by them so that the hospital staff are relieved of the need to interact with their users over these matters. Another development is the use of training resources to aid rehabilitation that do not take up staff time.

Sound Success: an online speech perception training resource. A presentation by Sandra Driver

Sandra Driver spoke about its development, how it works and user and professional involvement in its development.

Why develop 'Sound Success'?

This is an easy to use computer based online auditory and speech perception training resource.

29% or 7.6 million households in the UK are in sole occupancy. Computerised auditory training programmes now provide the option of training in a home environment without having to rely on others. Adults may benefit from this intensive aural rehabilitation programme that includes auditory training.

'Sound Success' is not the only rehabilitation resource available. Among the others in use are: Seeing and Hearing Speech (Sensimetrics); Sound Way and Beyond (Cochlear); Soundscape (MED-EL); The Listening Room (Advanced Bionics) and Talking Books.

Aim of Sound Success

Adults with hearing loss, both hearing aid and implant users, can benefit as well as some teenagers. It allows individuals to support their own progress without relying on others.



Photo: Jackie Ashley, Sandra Driver & Nigel Williams

1 November 2014 Technology Day at University Hospital of Wales, Heath Park, DIARY DATES Cardiff CF14 4XW. The workshop will be led by The Ear Foundation.

The listening activities are comprehensive and hierarchical – closed set moving to open set – to reflect the synthetic aspects of 'live voice' in clinic rehabilitation sessions. Functional real life vocabulary and everyday topics are used within each activity.

The 'Getting Started' section involves listening to paragraphs and sentences of varying lengths then everyday sentences and dates, times and prices. Individuals can then move on to the "Up and Running" section in which there are topic based sentences and a conversation between two people. Questions are asked to find out if the conversation has been followed.

There are other useful features. The learner can listen with the accompanying video so that lipreading is possible or without it and listen only. Background noise of various kinds – traffic or speech noise - and of different loudness levels can be introduced.

There are six different speakers, three male and

three female, with easy to challenging voices. Some speakers speak slowly while others have faster rates.

There is a self monitoring feedback from each section which can be recorded on a form and shared with professionals.

Users were asked about their reactions to the resource. At first they accessed the test site in the clinic and then from home. Access was for a maximum of eight weeks. All agreed they would recommend Sound Success and had found it helpful, interesting or even fun to use. It contributed to their confidence in communicating with family and friends and also unfamiliar people.

The site is now live:

http://www.absoundsuccess.com Vouchers to access the site are available from Advanced Bionics for each cochlear implant centre and for patients with Phonak hearing aids or and Advanced Bionic implant.

Batteries fail, Android to the rescue!

A few weeks ago I had some visitors staying with me, and we went out to explore one or two properties open as part of the Dorset Architectural Heritage Week. Hence it was very embarrassing when not only did the battery in my speech processor fail whilst we were out touring, but the spare battery I was carrying with me also failed.

Fortunately help was to hand, in that we had a couple of modern smartphones and tablet computers with us, both of which were running reasonably up to date versions of the Android operating system, and thence had its absolutely brilliant speech recognition system built-in. So we were able to fire them up and my visitors were able to speak into them and watch whilst a pretty accurate transcription of their words popped up on the screen for me to read! Obviously it's not perfect, particularly when used out of doors or in noisy situations, but in most cases it is remarkably accurate, and certainly is a great improvement on relying on others scribbling key words on the back of an envelope

to help you follow the conversation.

So if you have an Android smartphone or tablet computer bought over the last couple of years it might be worth experimenting with the speech recognition system to give you a fallback option if your implant is temporarily unavailable. If you go to the Android Play store there are dozens of word processing and notepad style Apps available for free download, once you've got one of them running and want to enter text into it you should find a microphone symbol on the on-screen keyboard. Tap on this and the system will go into dictation mode. I also send quite a few messages from my smartphone by SMS, if the message is more than a few words I find it easiest to dictate the message into Android, and if necessary go over the message and correct any errors before sending it.

Paul Tomlinson

Looping the UK

A summary of the presentation at the Summer Meeting by Dave King Hearing Link's User Experience Manager

Dave said he first heard about Hearing Link when they were running a campaign, 'Let's Loop Eastbourne', to raise awareness of hearing loops in Eastbourne. He stepped out of a thirty year career in journalism to work with them on this project.



A hearing loop provides a magnetic wireless signal which is picked up either by a hearing aid or a cochlear implant when it is set to 'T' (Telecoil) setting. A loop consists of a microphone to pick up the spoken word and an amplifier that processes the signal which is then sent through the loop cable. A wire is placed around the perimeter of a specific area such as a meeting room, church or a service counter. This acts as an antenna which radiates the magnetic signal to the hearing aid or cochlear implant.

There are all sorts of loops such as a room loop, counter loop and a portable loop. They help to make communication easier especially where there is ambient noise or poor room acoustics. They are used in shops, banks, post offices, cinemas, theatres, meeting rooms and other venues. In a noisy environment they enable the user to hear the one person they want to hear clearly even over a long distance. All cochlear implants have a telecoil facility.

Hearing Link

Hearing Link is a national charity which, in one form or another, has been around for more than forty years. In 2011 Hearing Concern amalgamated with the Link Centre for Deafened People to form Hearing Link. Our focus is the more than two million people

in the UK who wear hearing aids or have a cochlear implant along with a further two million who have a hearing loss severe enough to affect everyday life. By working with this community we also give people the chance to voice their opinions, share experiences and break out of the social isolation that accompanies hearing loss.

Creating loop awareness

Knowledge of hearing loops is poor not only in the hearing community but also among the hearing loss community. Many people have lost faith in the effectiveness of loops as they see the blue telecoil stickers in the shop window but find the loop is not working and the staff do not know how to activate it.

In a 'Loop Awareness Week' we work with volunteers along with organisations such as Rotary International and the National Trust to check hearing loops in public places such as shops, libraries, railway stations and churches. The volunteers look for three things: how good is the signage on the shop front; how good is the hearing loop inside; and how aware are staff of the hearing loop. There will also be places where there is no loop provision at all or it may not have been installed properly and not maintained or even not switched on.

The model is embarrassingly simple. On one hand there is a group of hearing aid wearers who are loop checkers. Secret shoppers of a sort! So far no cochlear implant users have become checkers but this may change. The volunteers are tasked to regularly check the hearing loops in the town and report back. When the loops are not working contact is made with the business concerned.



The guiding work is carried out by a steering group made up of key organisations in the town prepared to invest time to promote the initiative. In Eastbourne it is headed by Eastbourne Borough Council and includes representatives from the chamber of commerce, the clinical commissioning group, the chief NHS audiologist, representatives from the voluntary sector, tourism trade, hearing loop manufacturers and the media.

Over the past year there has been considerable change in Eastbourne in terms of awareness not only among hearing aid wearers but also the wider public. As a result more loops have been fitted. There is still much work to be done because the town is elderly demographic and there are a large proportion of hearing aid wearers.

One way of working is to run stories highlighting what hearing loops are, how they work and what impact they have on people's lives. One story was about a woman who was bitterly upset because the loop was not working in the crematorium chapel. She did not hear the eulogy given by the vicar to a close friend. The loop was fixed within a week!

On another occasion Hearing Link staged a loop awareness event at the Eastbourne Branch of Age Concern. The room was looped. The chief audiologist, Pauline Jenkins, started to speak but had hardly uttered a few words when a lady at the front in a broad London accent said, 'Excuse me love, can you speak up? I can't hear you.' When asked about the hearing loop the lady said she did not know what she was talking about. Pauline looked at her hearing aid and found it had not been set up for the loop. She then worked her magic and handed it back to the lady and there was a clamour for

Pauline's attention. Many folks at Age Concern had no idea about loops and their hearing aids had not been configured to the telecoil setting. One woman was reduced to tears when she suddenly found she could hear the voices of the speakers quite clearly.

'Let's Loop the UK'

The Eastbourne project, 'Let's Loop Eastbourne' has spawned 'Let's Loop UK'. It is a big and daunting task. Already projects have been set up in Surrey, Swindon, Chester and Newcastle in conjunction with deaf and hard of hearing groups. Hearing Link has helped to set up the groups, provide training and resources, but the groups work independently. All the projects are based on the Eastbourne model bringing together people with hearing loss and town partnerships.

In addition to this Hearing Link is establishing national partnerships with businesses and organisations such as Marks & Spencer, Sainsbury, Asda, Barclays Bank. HSBC, Nationwide and Halifax. In March Hearing Link hosted the first ever meeting of all UK's hearing loop manufacturers to seek a co-ordinated approach. It was the first time they had enjoyed a meaningful dialogue with hearing aid manufacturers. For example there was an earnest conversation between the two parties about Telecoil orientation and how Telecoil should be set to work more effectively with the loop. A further meeting is planned.

Dave ended his presentation by saying that hearing loops make a positive impact on the lives of people with hearing loss and he was determined to ensure the 'Let's Loop the UK' would create a positive environment for change.

Manufacturer's News

ADVANCED BIONICS LAUNCHES WORLD'S FIRST WATERPROOF CASE FOR COCHLEAR IMPLANT RECIPIENTS

Advanced Bionics (AB), a global leader in cochlear implant technology and a company of the Sonova Group, has announced the approval of the AquaCaseTM container in Europe, Canada and the US. Designed for use with the Naída CI Q70 (Naída CI) sound processor, the AquaCase accessory is the world's first and only swimmable, waterproof case for cochlear implant recipients.

From bath time, swimming and snorkelling, to skiing, trail hiking, mountain biking, mud running and rock climbing, the durable AquaCase offers recipients uncompromised hearing performance and peace of mind during even the most rugged adventures. To ensure it safeguards the Naída CI sound processor in any environment, the AquaCase features a security lock and special corrosion-resistant materials that stand

up to water, dirt, mud, sand, and other grime. Recipients can wear it just how they like it with a compatible clip, armband**, and lanyard.



"We understand how important hearing in and around water is for recipients and their families. First and foremost for safety and peace of mind, but parents also want their children to fully engage with their friends while playing in the pool or the surf," said Mark Downing, Director of Product Management and Surgical Support. "AB is always thinking of new ways to give our recipients hearing during life's adventures. This small, secure and incredibly durable case is another example of our commitment to the best hearing performance in every environment."

Advanced Bionics is the only company that enables cochlear implant recipients to enjoy fully waterproof hearing with no compromise in performance. The AquaCase accessory is designed for use with the swimmable AquaMicTM, AB's unique, IP 68-rated microphone. The AquaMic is 100% waterproof

and does not require a bag or enclosure that significantly reduces sound quality. Over the last three years, the AquaMic has delivered great performance to thousands of Neptune™ processor users; now it is available for recipients who use Naída CI processors as well. Delivering the industry's only headpiece-integrated microphone, AB allows Naída CI and Neptune™ recipients to wear the processor off the ear in the preferred location for any activity.

"At Advanced Bionics, we have always believed that hearing in and under water without compromising performance is essential to improve the quality of life for people with cochlear implants," said Hansjuerg Emch, President of Advanced Bionics and Group Vice President of the Sonova Medical Division where AB resides. "We are very pleased that with the introduction of the AquaCase for Naída CI, waterproof hearing is now available for the world's most advanced behind-the-ear processor."

The AquaCase accessory has been developed for use with the Naída CI sound processor available only from Advanced Bionics. With Naída CI, AB delivers a quantum leap forward in performance and wireless connectivity with a chic, modern instyleTM design.

To learn more about the new AquaCase from Advanced Bionics, please contact us at info.uk@ AdvancedBionics.com or visit **AdvancedBionics.** com

FROM COCHLEAR Launch of Nucleus® Profile™ with Contour Advance® Electrode

Cochlear is pleased to announce the launch of the Nucleus Profile implant with Contour Advance Electrode (CI512), which has just received regulatory approval in Europe. This implant is now available for all UK surgeons to use. Surgeons will be familiar with the Profile as it is based on the very popular CI500 series of implants which was launched in November 2009. The Profile with Contour Advance Electrode is

the thinnest cochlear implant in the world at 3.9mm. This makes it easier to implant and more discreet to wear for patients of all ages but especially young children.

The picture below the Profile sits just 1.7mm above the bone surface when

implanted. This means that hats and helmets are much more accessible for adults and children. This compares to a figure of 4.5mm for the next thinnest implant available.

More details can be found on the Profile and other product updates from Cochlear UK at our Facebook page (facebook.com/cochlearuk).



Figure 1. Necleus Profile Cochlear Implant against the skull

In Sync with Natural Hearing: The SYNCRONY System from MED-EL

MED-EL is pleased to announce the launch of SYNCHRONY – a new groundbreaking cochlear implant system created to bring together the latest implant and processor technologies for natural hearing in any listening environment. This revolutionary new system includes the SYNCHRONY implant, which is MRI compatible to 3.0 Tesla, and the SONNET audio processor, specifically designed to mimic the processing of sound more naturally.

Designed for superior MRI safety

Due to its unique and patented rotatable selfaligning internal magnet, the new SYNCHRONY implant allows MRI scans up to 3.0 Tesla, the current UK MRI standard for high resolution scans, without the need for repeat surgeries to remove and then replace the magnet. This represents the highest MRI safety on the market, and makes medical check-ups much more comfortable, quicker and safer for cochlear implant users. With the SYNCHRONY implant, users will have the peace of mind knowing they've chosen the only implant hat delivers exceptional hearing performance, outstanding reliability and unmatched MRI safety. The new SYNCHRONY implant's compact design also means it is the smallest and lightest titanium cochlear implant currently available - making it the ideal choice for people of all ages.

More natural hearing with advanced technologies

The new SONNET audio processor offers the latest generation of automatic sound management (ASM 2.0) representing MED-EL's goal to achieve more natural hearing and effortless listening for individuals with severe to profound sensorineural hearing loss.

It features:

- Dual microphone technology
- The latest advances in noise reduction technology
- Microphone directionality
- Wind noise reduction
- Automatic volume control
- Built in wireless connectivity
- Water resistant technology

The audio processor also actively adapts to any listening environment to ensure optimal hearing performance without compromise to its 60-hour battery life.

The SONNET EAS audio processor is now also available with acoustic amplification to provide Electric Acoustic Stimulation (EAS) for candidates with partial deafness. Both the Sonnet and The Sonnet EAS are fully compatible with the last 20 years of MED-EL cochlear implant technology. The RONDO single-unit audio processor is also available as an external component of the SYNCHRONY cochlear implant system. And with the new WaterWear optional accessory, the RONDO becomes fully submergible in water – ideal for bathing, swimming, and enjoying water sports.

Powered by Triformance

For the most natural hearing possible, MED-EL cochlear implants are powered by Triformance, the combination of three key technologies: Complete Cochlear Coverage, FineHearing and Structure Preservation.

For more information please visit www.medel. com.

Deaf Student wins National Award to help with studies

On Thursday 10th July, Councillor Ian Malcolm, Lord Mayor of Nottingham presented deaf university student Toby Carver of Wolverhampton, with a £6,000 CochlearTM Graeme Clark Scholarship Award at a ceremony in the city of Nottingham.

Toby, 20 years old, was diagnosed with profound hearing loss at the age of 12 months. He was fitted with a Cochlear™ Nucleus® implant when he was three, which was an event he and his parents say changed his life. Cochlear implants are electronic devices for adults and

children who cannot get adequate benefit from conventional hearing aids. Unlike hearing aids, cochlear implants bypass the damaged hair cells in the inner ear and stimulate the hearing nerve directly providing a sense of sound to users.

Toby says that deafness has many hidden difficulties. "It's not just about issues with hearing sound, but also causes problems with speech, communication and the ability to socialise. The cochlear implant has helped me so much and with lots of hard work and self-belief, I've



Toby Carver
managed to do well in my studies at school and
beyond. It hasn't always been easy and I still
hear new sounds and learn new words each
day."

"Most importantly, my cochlear implant has helped me to achieve one of my greatest goals in life which has been to apply to Bath University to study Civil Engineering. Learning about the complex and clever engineering of my cochlear implant inspired me, and I'm now really interested in how engineering can help humans work and how it keeps the world connected," says Toby.

Toby doesn't spend all his time studying and he loves football. He's tennis coach, a lifeguard and has recently become a ski instructor. "I'm so grateful to the manufacturers Cochlear for the invention of the implant and for all those at Nottingham Auditory Cochlear Implant Centre and in my local educational services for the support they have given to me. This award will help me through my four year masters degree." Lisa Aubert, General Manager of Cochlear Europe says, "The sponsorship is wonderful opportunity to help our recipients by supporting them financially when they continue their education. It also highlights how lives are enhanced through access to our technology, together with the help of healthcare professionals".

NCIUA's New Website

Readers may not be aware that the Association now has a new website.

This summer the Executive Committee commissioned a project to redesign the format of our website which has undertaken by Ben Glover, an IT specialist and son of our Secretary, Raymond Glover.

Still at the same address www.nciua.org.uk, this redesign as a modern layout with drop down menus and a fresh attractive layout. Built to modern website standards it is fully compatible with modern browsers such as Firefox and Chrome and is also accessible by mobile phones and tablets with Internet connection.

The structure of the content has been rearranged in part so that various pages are more logically connected. The content itself has been reviewed, refreshed and updated where known information is available. This is a work in progress and viewers are asked to send in any comments or suggestions they may wish to make.

To do this just use the Contact Us page. Fill in the details as indicated, tick the box marked Website, compose your message and click Send. As Webmaster I will be very pleased to receive any reviews comments or problems you may wish to raise and in doing so I thank you for your help so that we may continue to improve our website.

Richard Byrnes



News from the Home Counties Cochlear Implant Group (HCCIG)

OPEN MEETINGS

HCCIG have open meetings approximately 3 times a year. This gives all members the chance to attend and listen to professional speakers on issues relevant to all cochlear implant users. It is also a unique opportunity for all to network.

SOCIAL EVENTS

HCCIG members, friends, family or new people interested in joining have the opportunity to meet three times a year in a more informal setting. The event is dedicated to socialising and any issues, problems or information can be shared.

AFTERNOON TEA 8th October 4-7pm

Meet other CI users; find out more about Implants from people who have them. Southgate Beaumont Barchester Healthcare 15 Cannon Hill, Old Southgate, London, N14 7DJ Susan Copperwheat and Samantha Murray from MED-EL will be there to update us on the latest news. Should you have questions come along meet other CI users, find out more about Implants from the people that use them. Everyone is welcome, ample car parking space.

WINE BAR Tuesday 11th November Meeting 6-9.15PM

Brookes Brothers Wine Bar, 33 – 35 Brooke Street, Holborn, London EC1N 7RS. Nearest tube station: Chancery Lane on the Central line, Exit 2 End of year Lunch, Saturday 29th November This will be on at the Almafi Restaurant.

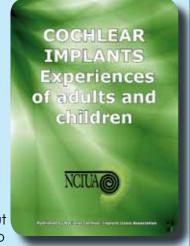
Christmas weekend in Eastbourne, Friday 5th December 2014 - Sunday 7th December.

For more information contact hccigs@gmail.com

Experiences Booklet

There has been a splendid response to our appeal for volunteers to contribute

to our new experiences booklet. It is being edited by Terry Emery who is an experienced writer and a cochlear implant user himself. If you have not already volunteered but would like to do



so please contact me: alisonheath71@hotmail.co.uk

Deadline for contributions to the next newsletter is 15th January 2015

National Cochlear Implant Users Association

President: Jackie Ashley *Chairman Nigel Williams

e-mail: chair@nciua.org.uk

*Vice Chairman Tricia Kemp

E-mail: vice.chair@nciua.org.uk

*Treasurer Paul Tomlinson

E-mail: treasurer@nciua.org.uk

***Secretary** Dr Ray Glover

The Vicarage, 70 Sycamore Road,

Amersham, Bucks. HP6 5DR E-mail: secretary@nciua.org.uk

***Editor** Alison Heath

E-mail: editor@nciua.org.uk Jenny Burdge, John Hirst,

Members David Williamson, Richard Byrnes,

David Cotter

Disclaimer

*Committee

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.

Registered Address:

NCIUA, 70 Sycamore Road, Amersham, Buckinghamshire. HP6 5DR Registered Charity No. 1073222