

Issue 50

Spring 2016 For people with Cochlear Implants



"Dunham Massey in the spring"



This newsletter has been produced on behalf of the Manchester CICADA Charity

contents

1 Editorial by Kevin Williams.

2 10 Tips to hear better from MED-EL.

3 Travelling about by Train Beryl Hardman's experiences.

4 Network Rail help for deaf children

4 Conference and AGM report by Kevin Williams.

5 MED-EL Childproof Sonnet equipment **6-7 What would you do? Case studies** by John Newton.

7-8 Hearing Dogs in the family by Beryl Hardman.

8 AOHL and Advanced Bionics funding for PhD

- 9 Notes for the diary
- **10 Hedy Williams obituary**
- **11 A Visit to Rome** by Dal O'Mera.
- **11** ReSound 'Notes' section

Editorial

Welcome to the Spring edition of Resound. It has been an eventful first few months of 2016 in many ways. The AGM, held for the first time in Warrington and hosted by a new organisation has by all accounts been a success.

In March we lost our Secretary and Resound Editor when Hedy lost her battle against cancer but it brought many of us together as a group and showed just how close an organisation we are and for that we thank you.

As is necessary these days the Xmas meal has already been booked in Liverpool at a new venue and we look forward to welcoming as many of you there as we can.

We have an outline schedule of events in this issue which covers the rest of the year and by the time you read this we will already have met up at the first event on the list in Preston.

The ethos of this charity has always been on helping others and CICADA members continue to assist in research carried out by the staff at the Implant Centre in Manchester to improve the quality of the cochlear implant processors. We are also engaging with the NHS in order to try and improve the communications experience for deaf people when they have to stay in hospital and we will keep you updated on progress throughout the year.

Once again everyone on the EC thanks you for your continued support and we look forward to seeing you throughout the year.

Kevin Williams Editor

1

10 tips to hear better at family gatherings

Getting together with family and friends, for holidays or parties or just for fun, can be enjoyable—but all those people can also make it difficult for someone with hearing loss to hear well. If you want to hear better in times like these, here are some simple tips that you can use.

Talk About your hearing loss

The best way to hear better is to start with talking about your hearing loss.

For new friends or others who might not know you have a hearing loss, just let them know and say that you use a hearing implant to hear. And even if they already know that you have a hearing loss, a reminder won't hurt; sometimes people won't recognize if a specific situation is especially challenging. So if you're having difficulties hearing, just say it.

Give Them Communications Tips

In some situations you might be tempted to keep your distance from people, or take a break from a crowded room and go to a quiet place. Although this could work as a short-term solution, it's not an ideal way to deal with the fact that it is difficult to hear in some situations.

Here are some easy things that you can ask them to do:

Move closer and speak towards your implanted ear—or if you have bilateral implants, towards your better ear.

Ask them not to shout, but to speak clearly and in a normal voice. Some people without hearing loss assume that if they speak louder they will be easier to hear, so the only way to change that is by letting them know that it doesn't.

If you didn't hear a word or sentence, don't be afraid to ask them to repeat what they said.

Ask them to face you when you are speaking, because that way you'll be able to pick up on

their non-verbal communication.

If you're in a group, sit or stand where you can see everyone's faces. If you need to, ask them to take turns so that you can follow the conversation and don't have to listen to people talking over each other.

Make a Good Listening Environment

Your environment also has a big impact on how well you can hear. For example, having lots of background noises can make it difficult for anyone to hear, even if they don't have a hearing loss.

If you're in a noisy place, like where there's a TV or stereo turned on in the background, move to another room if possible. Or if it's just been left on and nobody is watching or listening to it, just turn it off.

If it's too dark and you can't see their faces, ask to move to somewhere else that is well-lit.

If there's too much noise around to have a conversation with one person, just move to a quieter corner or another room where there isn't so much noise.

If your conversation is interrupted by a loud noise that you know will end soon, like a loud truck driving by, just take a quick break and wait for it to pass.

Use an assistive listening device, like a neckloop with a remote microphone. This way you can put the microphone near whoever is speaking and hear them even if you're on the other side of the room.

The feeling of not being able to hear can be a big source of anxiety, so try not to stress yourself about it. With these simple steps you can know that you're working to hear better regardless of the situation.

This extract is from the Med-El Blog on their website

Travelling about by train

by Beryl Hardman

How many of you travel by train and have difficulty in hearing announcements? So much is being done on rail improvements, with re-vamped stations, in Manchester Victoria`s case, looking like the Eden project with the glass domed roof! It certainly takes away the dark Victorian look and makes for a more pleasant environment. New ticket machines have been installed for the help of a better flow of passengers and a Metro link also is in place, so you can hop off the tram onto a train.



Yet, what have they done for the deaf travellers?

We are still subjected to the garbled announcements on both platforms and trains. Fortunately we now have TVs on most platforms, which state the destination of the next train and stopping places en-route.

But, this does not help if you are travelling on a train in a strange area and cannot hear the announcements for each stop. Not all trains have what I call electronic subtitles giving you the next stop!

I was impressed with the article I posted on Cicada Website concerning a Paul Lennon, who is deaf and had struggles in his life trying to overcome this disability. He had many jobs, but due to sheer determination and study he is now Community Relations Executive for Network Rail. He gives talks to school children, but this seems to be in the Southern Region, so I hope in the future he could widen the area to us Northerners! I also hope he can help improve facilities for the deaf, as there seems to be more concern for the blind.

Some time ago I was traveling to Buxton from Blackpool when an announcement was made, which I presumed was to do with the next stop. Engrossed in my book I suddenly realized we were going backwards, and found I was nearing Lancaster. On voicing my concern to fellow passengers, who were getting off at Lancaster, they very kindly took me to the station master's office and explained my dilemma.

The station Master then put me on a train to Preston, and en-route I texted my daughter who came to Preston to pick me up.

I never arrived at Buxton, and by the end of the journey I was extremely stressed and need of a stiff drink!! All this was before we had TVs on our local station, so that addition is helpful. I am hoping as time goes on we get more consideration and help, maybe Paul Lennon is our answer.

A role model and rail safety for deaf schoolchildren from Network Rail

Deaf schoolchildren from across Essex enjoyed advice and inspiration during a visit to St Clere's school in Stanford-le-Hope from a deaf member of Network Rail's Community Relations team. Paul Lennon is a community relations executive for Network Rail, he's also deaf – so when he was



"I know the teacher at the school and he set up a day where deaf children all over Essex could come along and learn what they can achieve in life," says Paul. "Some think being deaf means you can't do something or you're disabled – which isn't the case. I've faced barriers in my career, primarily due to lack of understanding – but they can be overcome."

Paul Lennon, Community Relations Executive

approached to host a talk for deaf schoolchildren, he jumped at the chance.

Paul's own career has been truly varied; he's been a head chef, works for a charity for the deaf, and last year completed his university degree in law before joining Network Rail early last year. His role in the communications team at Network Rail includes investigating queries and complaints from members of the public, councillors, MPs and passengers, as well as holding community engagement events in the run-up to planned improvement works. Paul uses a variety of ways to communicate including using an interpreter and email.

"I wondered about the perception of a deaf person within the organisation but actually I've been delighted. The attitude towards me in Network Rail has been great and I believe I've fitted in well and achieved a lot so far – it's all been very positive."

The talk was also an opportunity for Paul to remind the children about level crossing safety – and importantly, in a way that was accessible for them.

We were delighted that Paul was able to join us at our Deaf Role Model Conference to share his experience with our deaf students.

His presentation brought two important elements that are essential to young deaf children; that it is acceptable to have barriers throughout their upbringing and how to overcome them, and the importance of rail safety. The session was not only very inspiring but featured powerful safety messages.

Paul Newbury, deaf instructor for British Sign Language from St Clere's School said 'It really went well. There's a lot of safety information on level crossings out there that the deaf community might have seen but not quite understood – so I think it's important for the kids to be able to access this in sign language. They really engaged with the topic'.

Paul hopes that his diverse experience and success story will leave a real impression on the children, encouraging them to always aim high and focus on what they can do – not what they can't. "I wanted to show them that they can achieve the same things others can – the only thing we can't do is hear and my point to the children was if you work hard and don't give up, you can achieve."

CICADA Conference and AGM Warrington March 19th

The Conference and Annual General Meeting of CICADA took place on the 19th March at Warrington this year. We were trying out a new venue this year, having had the last couple of meetings at Stockport College. The Flexible Meetings Organisation provided us with a purpose built modern air-conditioned centre at Birchwood in Warrington.

The guest speaker was from Hearing Dogs for the Deaf and came with a user and her friend who was lovely. The presentation was very informative and everyone enjoyed it. After a buffet lunch we held our AGM and there were some changes voted in. The new chairman is John Newton, I have stepped down and taken over the Secretary's job and Bill Allen has stepped down from the EC after many years dedicated service and we all thank him wholeheartedly for everything he has done for CICADA over the years.

NEW child-proof DL-Coil for SONNET now available



Good news from MED-EL: The new DL-Coil, which offers enhanced safety features and customisation options, is now included as a patient kit choice for the SONNET and SONNET EAS.

The child-proof design of the DL-Coil makes the SONNET audio processor the ideal choice for parents considering an upgrade from the OPUS 2, as well as new MED-EL cochlear implant users. Thanks to the indicator lights, the DL-Coil provides parents with even greater peace of mind, knowing that their child is always connected to the best possible hearing. A quick glance confirms sound transmission to the implant.

Other child-friendly features include:

5

Lockable Connection and a Tamper-Proof Cover - The new locking cable connection provides added safety and security; the cable cannot be disconnected without first removing the new tamper-proof cover.

Durable Cables - Reinforced coil cables are available in four colours and three lengths.

Adjustable Magnets - Five magnets with adjustable strengths can be easily fine-tuned by the clinic for optimal comfort and security.

Exchangeable Covers - 12 interchangeable covers provide simple and inexpensive options for customisation.

Sleep Mode - To conserve battery life, sleep mode can be activated – reducing battery drain if the processor is removed but inadvertently left switched on.

With an IP54 water protection rating, the SONNET with DL-Coil is splash proof. For complete waterproof protection, the new WaterWear is the ideal accessory allowing users to enjoy a swim in the pool, or a leisurely soak at bath-time, without ever missing a moment of sound. The new DL-Coil is compatible with the SONNET and SONNET EAS when used with any MED-EL multichannel cochlear implant, including: the revolutionary SYNCHRONY, as well as CONCERTO, SONATA, PULSAR, C40+, C40 implants. (N.B. link-check function is not available when used with C40/C40+ implants).

To discuss your eligibility for the DL-Coil with your current SONNET processor, or your upgrade to the SONNET, please contact your audiologist/CI centre.

For more information about the SONNET, the DL-Coiland WaterWear, visit www.medel.com/uk/info

What would you do?

by John Newton

A Cochlear implant (CI) is a wonderful thing but it will not allow you to have perfect hearing. It will however restore your confidence in coping with the world. The case studies below describe situations which could face someone who has been deaf for some time and has just received their CI. They are the sort of situations which can be very challenging; impaired hearing can lead to a disastrous loss of confidence.

Read them and ask yourself what you would do if faced with similar situations.

RAIL TRAVEL

Jack is en route to London from Manchester by rail. When he gets to the station he sees the indicator board which should show his train says "all London trains delayed". It's a busy day and there is a long ragged queue at the entrance to the London platform. The PA system is making announcements which Jack can hear but cannot understand. There are two officials in tabards obviously trying to help the passengers but each is surrounded by a scrum of enquiring passengers. It is of course very noisy. If Jack is seriously delayed, he will miss an important rendezvous in London, He is desperate to find out what's going on and begins to feel panicky that he will miss out when a train is announced.

GYM ENCOUNTER

Jill is a regular at the gym, one of the other members is a very garrulous friendly woman often there at the same time as Jill. However Jill has to remove her CI when she goes in the pool and shower and finds it very embarrassing when the friendly lady tries to talk to her. She tries to get by by nodding and smiling but this, if anything, increases her embarrassment. She would really like to return the friendly gestures, it's one of the reasons why she goes to the gym.

CINEMA FRUSTRATION

Michael is a film buff and likes to watch films on TV or via streaming services which mostly have subtitles. However he still likes to go to the cinema, particularly for some films particularly like "Gravity" which are exciting to see on the big screen, he also likes to see new films and not have to wait a year until they become available at home. With his partner a cinema visit makes an enjoyable night out and they like to have a meal afterwards. He also knows that most feature films shown in cinemas nowadays come in digital format with subtitles included in the recording. However, when he looks at the programme for his local cinema, he finds that only 3 or 4 of the dozen or so films on show each week have captioned screenings and then often the lighter fare and often during the day when he is at work. He finds it intensely frustrating particularly when he has just read a rave review of a film in the paper.

SHOPPING TRAUMA

Priti is a keen cook and lucky enough to live near a proper old fashioned food market. She tends to go there on Saturday when she has more time for creative cooking and the corresponding shopping. There is a really good greengrocer. It has a wide counter packed with attractive fruit and vegetables and the staff stand behind it slightly higher so she has to talk across this display. Normally she is served by a pleasant typically cheerful market woman but on this particular day she is not there and she is served by the male colleague (husband?) who rather overdoes the role of chatty market trader and indulges in lots of banter with his customers, playing to the gallery somewhat. Priti usually tries to avoid him. When she hands over her chosen purchases for bagging, he says something to her, clearly intended to be humorous which she doesn't hear.

She says "Sorry?" and the man repeats the remark very loudly and in an exaggerating manner with glances at the other waiting customers which clearly invite applause at his wit. Priti finds this intensely annoying and embarrassing.

HOSPITAL WOES

Paul has broken his wrist two weeks ago and is at the local hospital fracture clinic, which is very busy. The clinic is so busy that there is a queuing system just to check in where you take a numbered ticket and wait for someone to call out that number. He chooses a seat where he can see what's going on and hopes he will hear when his number is called. He waits a long time and eventually goes up to the desk and asks, diffidently, how much longer he is likely to have to wait. He knows his check is fairly routine and he asked his wife to pick him up after an hour (he cannot drive because of his wrist). The receptionist is short with him "What's your number?" She is ill tempered and harassed. He shows her his ticket and she rolls her eyes at him and at her colleague, "Why didn't you respond when we called the number?" she says. Paul is embarrassed and frustrated. She makes him feel like an idiot.

ON THE FELLS

David is a keen walker, he is also single, his wife died a few years ago.. He finds it difficult to follow a conversation when there are more than two people involved. His friends keep telling him he should get out more and he decides to join a walking group, a branch of the local Ramblers Association. He joins them at the chosen rendezvous and they are all very welcoming as they set out on their hike. He is pleased to be there, they are a jolly and interesting group. He feels he's been avoiding company too long. A pleasant woman about his own age, walks alongside him and engages him in conversation. He finds rather to his horror that he cannot hear her without looking at her and of course he has to look where he is putting his feet and where he is heading. It's not a very difficult walk but it's not a city pavement. He feels almost a sense of panic.

There are no right answers of course. Confrontation is not always advisable although it is nearly always a good idea to explain that you are deaf. If you do complain it's best to keep smiling and contain your resentment, it's more effective in the long term. (although it is probably sensible just to swallow hard and walk away from the boorish market trader).

Hearing Dogs in the family

by Beryl Hardman

I became interested in hearing dogs when my Great Niece was allowed one. She has been deaf from birth and fought valiantly against her disability. At the age of about 2yrs she had bi-lateral



implants, after struggling with two hearing aids, often pulling them out.

The implants made so much difference to her life, yet she was coping with sounds she had never been able to hear in her young life. She had to learn to speak, something a normal hearing person takes for granted. The process takes much longer than an adult, especially one who has known some hearing.

She now takes part in lots of activities, and plays football in a girls team. She now speaks beautifully and is doing well at a school for the deaf where there is a more one to one teaching, due to smaller classes. She has had the Hearing Dog now for about 12 months, and they have bonded. I was fortunate to have met him recently and was very impressed at how he responded to various sounds. He doesn't bark, but responds by body language.

For those of you who were at the AGM at Warrington you will have seen first hand at the ability of the Hearing dog, who came with his Carer. The speaker gave a very interesting insight into how the dogs are trained, and the length of training where they have volunteers for this as well as how they are introduced to their new carer. The introduction takes place at the centre to see how they react and respond. Then they have to see if the home environment is suitable. A safe garden is also important. Certain breeds are more suitable to this job than others, my



Niece's is a cross between a Spaniel and a Poodle, but there are also Labradors and Spaniels.

All this is done by a charity who rely on donations as well as volunteers to carry out their good work.

The first photo is Mac my great Niece's dog & second is the AGM hearing dog, not sure what he was called.

AOHL and Advanced Bionics fund PhD

UK charity Action on Hearing Loss (formerly RNID) has teamed-up with Advanced Bionics, a global leader in developing cutting-edge cochlear implant technology which can allow deaf people to hear, to jointly fund a PhD studentship at University College London (UCL).

Cochlear implants directly stimulate the auditory nerve allowing people with severe-toprofound hearing loss who are not benefiting from hearing aids to hear speech. Over 11,000 people in the UK use cochlear implants, but the quality of hearing can vary between individuals - particularly when there is a lot of background noise.

Dr Debi Vickers, Principle Investigator at UCL Ear Institute said, "The current one-size fits all approach to programming cochlear implants could be part of the reason why benefit varies between people using implants.

"Our new project aims to determine whether individualized settings will improve the ability of people using implants to understand speech in difficult listening situations, such as when speech is presented at a quiet level and in the presence of noise. If a clearer approach to fitting implants can be found, it will lead to improved NHS guidelines for cochlear implant services in the UK."

Patrick Boyle, Senior Director of Global Research at Advanced Bionics said, "We are delighted to be working in partnership with the UK's only charity that is dedicated to funding research into hearing loss to support the training of a PhD student in an area of research, which will further improve the quality of life for people who are deaf."

Dr Ralph Holme Action on Hearing Loss' Head of Biomedical Research said, "It's fantastic to be working with Advanced Bionics, investing in the next generation of scientists able to develop ever better cochlear implant technology helping deaf people around the world to live the life they choose."

Action on Hearing Loss runs the world's largest donor-supported hearing research programme, dedicated to funding research into better treatments and cures for hearing loss and tinnitus.

(This article appeared in a recent issue of the Hearing Times)

Notes for the diary

Here are some of the events that we are planning for the year, we would appreciate some feedback especially for the coach trip so we get get some accurate quotes so if you are interested in coming to an event or want more information please get in touch as soon as you can. We would also welcome any ideas you may have for an event.

Month	Name	Location	Comments
June	Elizabeth Gaskell House	Manchester	Lunch and tour with LipSpeaker 28th June
July	Lunch and visit	Lake District	Coach trip -Bowness- Boat tip-Lunch w/c 18th July
August		Altrincham	Pub Lunch
September	St George's Hall	Liverpool	Lunch and Tour
October	Ring O'Bells	Daresbury	Lunch and Lewis Carroll tour
November	The Liner Hotel	Liverpool	Xmas Lunch 26th November
December	The Mill Hotel	Chester	Lunch and shopping
January	Per Tutti	Deansgate Manchester	Lunch
February	Italian Orchard	Preston	Lunch
March	Conference and AGM	(tba)	

StageText productions for 2016

Manchester Palace Theatre (Captioned by Stagetext) T: 0161 245 6605 or 0844 871 7677 emailmanchesteraccess@theambassadors.com Website: http://www.atgtickets.com/venues/palace-theatremanchester/

MAMMA MIA! (Tour) - Wed 25 May 2016, 7:30pm *Billy Elliot The Musical* - Tue 24 Jan 2017, 7:30pm Age Recommendation: 8 years and above.

Octagon Bolton (Captioned by Stagetext) T: 01204 520 661 E: boxoffice@octagonbolton.co.uk W: https://www.octagonbolton.co.uk/whats-on *The Macbeth Curse* - Fri 22 Apr 2016, 7:00pm 'Terry Deary's brand new play is a perfect introduction to the magic and madness of Macbeth. Recommended for age 7 years and over. Director: Mark Powell. *Look Back In Anger* - Thu 28 Apr 2016, 7:30pm John Osborne's seminal play. *Singin' in the Rain* - Fri 17 Jun 2016, 7:30pm Featuring all your favourite songs from the MGM film *Cinderella (Bolton)* - Fri 16 Dec 2016, 7:30pm **Royal Exchange Theatre** (Captioned by Stagetext) T: 0161 833 9833 E: box.office@royalexchange.co.uk W: http://www.royalexchange.co.uk/ *King Lear* - Fri 29 Apr 2016, 7:00pm *The Night Watch* - Wed 15 Jun 2016, 7:30pm Directed by Rebecca Gatward. *The Mighty Walzer* - Tue 19 Jul 2016, 7:30pm Directed by Jonathan Humphreys

The Grand Theatre, Blackpool (Captioned by Stagetext)

T: 01253 290 190 E: box@blackpoolgrand.co.uk W: http://www.blackpoolgrand.co.uk/ *A Midsummer Night's Dream*: A Play for the Nation (Tour) - Fri 8 Apr 2016, 7:15pm

The Lowry (Captioned by Stagetext)

T: 0843 208 6000 E: boxofficeadmin@thelowry.com W: www.thelowry.com *The Herbal Bed* (Tour) - Thu 31 Mar 2016, 8:00pm A co-production with Royal and Derngate and Rose Theatre Kingston. A play about life in Shakespearian England.

Hedy Williams 1951-2016

We are sorry to tell you that Hedy Williams, the Secretary for CICADA, and the editor of our Resound magazine, died on March 10th after a short illness at the age of 64.



Hedy was born with a hearing loss and lived all her life in the Manchester area. She was born in the Audenshaw area and her hearing problems caused her difficulty at school as she was unable to follow lessons and her behaviour was misunderstood. But she always excelled at art which led to her first job in a drawing office, where she first met Kevin, who was an apprentice there. Kevin and Hedy married in 1974 and set up home in Bredbury. Kevin and Hedy had one daughter, Paula.

For many years Hedy was self-employed and ran her own desk top publishing business, and later Hedy and Kevin set up their own contracting and publishing company which they ran until their retirement. This stood Hedy in good stead when she became Editor of Resound.

Hedy's hearing deteriorated all through her life until she reached the point where she was profoundly deaf. Even at this stage she continued to run her typesetting business communicating with her customers by fax. All of her skills and knowledge about the computers and software she used were self taught from manuals as in those days there was little or no support for deaf people to attend commercial training courses.

Hedy had been an outpatient at the MRI for some time until they could no longer supply her with an appropriate hearing aid but she became eligible to have a cochlear implant and was put on the programme.

She had her cochlear implant about fourteen years ago when the operation was still quite new and was operated on by Professor

Ramsdens team. This is where she became aware of the Manchester CICADA club, as it was then, set up by, one of the pioneers of the operation, Professor Ramsden and a patient of his, Laurie Clearey. The idea of the club was to provide post operative support to patients who had had



an implant . The club later became a charity and both Hedy and Kevin were actively involved in this, and Hedy also acted as Editor of NADP's journal, Network.

Hedy trained at university as a lip-reading teacher and gained her certificate in 2009, after which she taught classes in Stockport for a couple of years. Both she and Kevin were also Trustees of NADP from 2011 until 2014.

Hedy was always a caring and loving person. She had a good sense of humour and a droll wit. She was very independent over the years despite her hearing loss. She was also a good cook and loved experimenting. She will be greatly missed by all of us who had the honour of knowing her and working with her.

Hedy's Obituary is also on our website where you can leave your thoughts.

A Visit to Rome

by Dal O'<u>Mera</u>

I've just recently returned from a trip to Italy taking in (among other places) Rome & Pompeii.

we couldn't use this with the ear buds so we were given headphones. This happened again

I was with a friend who had digital hearing aids.

Visiting St Peter's Basilica we found that the tour was via audio only. Technically it should have been ok for me as I have a media lead attached to a second battery cover (see pic) but I didn't have it with me so the audio unit was useless. My friend couldn't use it either. On our tour of the Sistine chapel it was



at Pompeii but they didn't have headphones so we had to stay close to the guide.

The moral of the story is that if you are going somewhere where there is likely to be audio info (here or abroad) either take your own headphones or if you have a media connection on your CI unit don't forget to take it with you!

I did actually use that at the Empire State building tour a couple of years ago & it worked fine. Apart from that the trip was wonderful.

audio again but via a guide. My friend & I said

ReSound 'Notes' section

We welcome contributions from members on any subject that would be of interest to others, (including your CI experiences) your recent experiences with the health service, meet ups, activities or other news about yourself.

If you have something that you think may be of interest to others email it to

or fill in the form online at http://www.manchestercicada.org.uk/resound-2/

or write to: Kevin Williams, 107 Manchester Road, Hyde, Cheshire SK14 2BX.

A big thank you to contributers to this issue, Beryl Hardman, John Newton and Dal O'Mera

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