

For people with Cochlear Implants

Autumn 2022

Issue 75



The colours of Autumn



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

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Editorial

Welcome to the Autumn edition of Resound for 2022.

In this edition we have contributions from several members and also the encouraging news that we have finally restarted meetups and events.

We have reports on two of these in this edition and will be organising more now that we are in a better position to do so.

In order to make these events more acccessible to our widely scattered membership we are focussing on organising local geographically targeted events based on smaller groups of people with the aim of allowing more people to meet with others in their area.

We are also getting involved with other organisations such as ATLA, having attended their recent conference in Manchester where we were representing CICADA.

Support for potential Cochlear Implant users has always been at the forefront of

our activities as is working with the implant clinic.

We are always looking out for pictures or short stories about activities that you have been involved with locally such as the Southport Kite event for example so if you have anything you've been out to see let us know.

We have a section on our website with lots of photographs of memorable events that have been run over the years so feel free to browse at:

www.manchestercicada.org.uk

A big thanks to all those who have supplied articles and photographs for this issue its much appreciated..

We hope you find this issue of some help and if you've any comments, or stories to send along please let me know.

Kevin Williams - Editor

WHAT CAN YOU SAY?

by John Newton

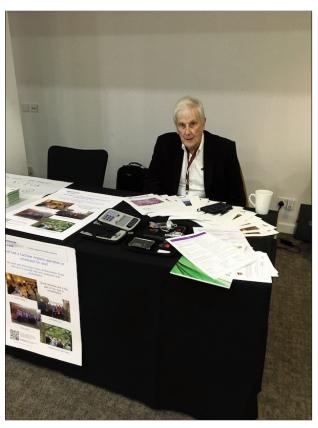
CICADA recently found itself in a rather smart conference room in Manchester having been invited to be part of the annual conference of The Association of Teachers of Lipreading to Adults (ATLA) whose purpose is clearly reflected in their title.

Our role was to represent CICADA and explain what we do to the delegates who are of course professional teachers of lip reading and with lots of background among deafened people.

I was a bit surprised that of the various conversations I had, the reluctance of possible candidates for a CI to go through with the implantation was raised several times. This reflected other conversations I have had in other places. It seems not uncommon for patients who acknowledge that getting a CI is for their long term good but stall at the starting line.

I was told one story about a woman who changed her mind at the very last minute and fled the hospital when she was being prepped for the operation.

There seem to be various reasons for this. A natural fear of the surgeon's knife, an apprehension about the irreversible nature of the procedure, and doubts about its effectiveness. My own experience of making this decision is now more than ten years in the past. What I do remember



was that I was given a lot of time to think and a good few visits to the clinic over a period of several months before I was, quite formally, sat down in an interview, with an audiologist and a surgeon together, and offered the option.

Would I lose any residual hearing in the implanted ear was one of my questions to which, at the time, there did not appear to be a definitive answer. My other worry was the effect on my health of the general anaesthetic. I was 71 at the time and a bit asthmatic.

It's a marvellous invention, but it is understandable that it can be worrying for some. So what should veterans of the procedure say to worried candidates? I think it would be quite irresponsible to offer too much reassurance. Everyone is different and even the experienced professionals cannot be sure about the outcomes of the implantation.

I think we have to resist the temptation to dismiss the fears airily and say "it was great for me, it's wonderful etc". We should I think confine ourselves to recounting the effects we experience personally and rationally. I am very happy about my own experience

even though I can no longer hear the music I used to love. Without this thing stuck to my head I would be in a much darker place.

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I do think it is marvellous invention and when I meet someone who says they are thinking about it I do recommend them to start the process at their CI clinic.

What happens after that is down to the professionals and the recipients' individual and carefully considered decisions.

Accessible Banking for Deaf People: My Experience (Part 2) by Deaffie Blogger

Last year I was looking for a bank to open a new account with. When choosing a bank, many customers' priorities may be; high interest rates, reward schemes or good customer service. For me, my main filter is accessibility.

Due to previous problems I had with my original bank; HSBC, I felt that I needed a bank with a high street presence to enable a face to face encounter if necessary, as well as good accessibility.

After intensive research, I decided that Barclays looked my best bet. The Accessibility Statement on their website looked promising. I felt confident reading about their commitment to 'become the most accessible financial services provider'. Many of my D/deaf contacts and friends also advocated Barclays.

Setting up an account:- I made an appointment at a large branch in my nearest city for a face to face meeting to ensure they would meet my needs. It was important for me to be assured that I could access it before opening the account, namely assurance that I would be able to access Telephone Banking through a third party. Once I had this guarantee I went on to open an account.

I then had a lovely meeting with the personal banking representative, explaining previous problems and my individual requirements as a deaf customer.

Coming to a resolution:- After opening the account, my Mother and I tried out telephone banking. Unfortunately it didn't work. The staff informed her I couldn't access my account through a Third Party which was disappointing at first, but I was hopeful we could find a workable compromise.

Although at times, the process appeared time-consuming, frustrating and long winded, Barclays and I reached a very satisfactory resolution.

To my followers and supporters, it seemed at times that there was little I could report when we were proceeding behind the scenes to resolve the issue. The main challenges both banks and customers face are security, data protection and accessibility, all equally important, to achieve a solution involves close regard to them all.

It soon became apparent that Barclays accepted the predicament many D/deaf people face, and wanted to work together to establish a method which would work for both parties, which was secure. To my delight, they developed new technology to alleviate

this problem!

New Lipspeaker Service:- I worked closely with Barclays to bring out their new Lipspeaker Service, whereby a customer can contact them with a Lipspeaker speaking on their behalf.

For this to work, you have to register your details with them beforehand so they can add a 'confidential care indicator'.

This means when making a phone call to Barclays with your Lipspeaker, you will have to 'pass some initial security questions, you'll then be sent a one-time passcode by text message to the mobile telephone number (they) have for you. You simply relay that back to (their) team and (they are then) happy to help.' This means that no one is able to access my bank account without me being present, therefore it is secure.

More info: https://www.barclays.co.uk/accessibility/hearing-or-speech/

Meeting the Team!:- Before the news of this technology was released, I was invited to Barclays Head Office to meet with the two wonderful staff members who were instrumental in bringing out this change, to try the system out for the first time. It worked perfectly. We had a positive and productive meeting discussing D/deaf awareness in general.

Safe but accessible:- Even though it took a while to resolve, I was happy that Barclays took my issue seriously and took steps to overcome the barrier I faced. This new service allows both parties to be satisfied, both securely and accessibly.

No solution can claim to be perfect. I have to always make sure my phone is charged and I have a signal and the process takes a little longer than a conventional phone call, but as we all know, having a disability means things can take longer, it's something we accept... as long as it solves the problem then that's all that matters.

My main inspiration and drive was to improve accessibility for other deaf people and I'm happy that Barclays was willing to come to a workable compromise, helping us to become more independent. We are hopeful more D/deaf people will take advantage of this significant provision to overcome this common problem.

Moving forward:- This experience has shown me that there are organisations willing to invest the time and effort to make services more accessible for customers with additional needs. Even though I wasn't sure big banks would listen to little old me... perseverance and patience paid off.

I am extremely heartened to know that Barclays is committed to become more



accessible with a view to meeting the needs of its D/deaf customers.

My advice:- The advice I would give is; if you feel a service is not accessible, approach the organisation, explain your difficulty and ask if they can provide an accessible alternative. Hopefully they will listen, as Barclays did, and work with you towards a mutually beneficial solution.

I feel proud of this achievement and secure in the knowledge that change for the better is always possible.

Deafie Blogger - http://www.deafieblogger.com

Breakthrough in search for tinnitus cure

from research carried out by University of Auckland

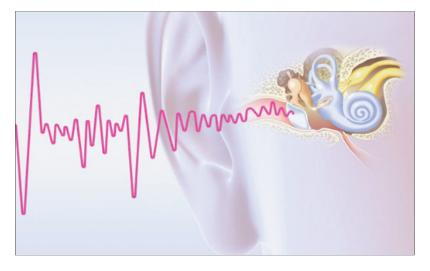
After 20 years searching for a cure for tinnitus, researchers at the University of Auckland are excited by 'encouraging results' from a clinical trial of a mobile-phone-based therapy. The study randomised 61 patients to one of two treatments, the prototype of the new 'digital polytherapeutic' or a popular self-help app producing white noise.

On average, the group with the polytherapeutic (31 people) showed clinically significant improvements at 12 weeks, while the other group (30 people) did not. The results have just been published in Frontiers in Neurology. "This is more significant than some of our earlier work and is likely to have a direct impact on future treatment of tinnitus," Associate Professor in Audiology Grant Searchfield says.

Key to the new treatment is an initial assessment by an audiologist who develops the personalised treatment plan, combining a range of digital tools, based on the individual's experience of tinnitus. "Earlier trials have found white noise, goal-based counselling, goal-oriented games and other technology-based therapies are effective for some people

some of the time," says Dr Searchfield. "This is quicker and more effective, taking 12 weeks rather than 12 months for more individuals to gain some control."

There is no pill that can cure tinnitus. "What this therapy does is essentially rewire the brain in a way that de-emphasises the sound of the tinnitus to a background noise that has no meaning or relevance to the listener," Dr Searchfield says.



Audiology research fellow Dr Phil Sanders says the results are exciting and he found running the trial personally rewarding.

"Sixty-five percent of participants reported an improvement. For some people, it was lifechanging -- where tinnitus was taking over their lives and attention."

Some people didn't notice an improvement and their feedback will inform further personalisation, Dr Sanders says.

Tinnitus is a phantom noise and its causes are complex. It has so far defied successful treatment.

While most people experience tinnitus, or ringing in the ears at least on occasions, around five percent experience it to a distressing degree. Impacts can include trouble

sleeping, difficulty carrying out daily tasks and depression.

Dr Searchfield says seeing his patients' distress and having no effective treatment to offer inspired his research. "I wanted to make a difference."

The next step will be to refine the prototype and proceed to larger local and international trials with a view to FDA approval.

The researchers hope the app will be clinically available in around six months.

Story Source:

Materials provided by University of Auckland. Note: Content may be edited for style and length.

Invention of Cochlear Implants

by Norah Clewes

I lost all my hearing in 1956 when I was nearly seventeen, studying Chemistry and Biology in the 6th form at

school.

For forty years I managed with total deafness using lip reading and text. My parents and family and friends encouraged me to do what I wanted in social life, education and work. Their attitude was just get on with it and do your best. I was really lucky to have them.

I went on to University

where lecturers gave or lent me copies of their notes. These made me popular with other students who copied them too! After University I went to work in the laboratories of a paint company where I met David who became my very patient, caring and understanding husband.

I had given up hope of getting any hearing back but in 1996 after various tests and trying a external single electrode device I was able to have a multichannel implant at Manchester Royal. After time for the wound to heal I went back for the audiologist to tune the implant. She

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connects the transmitter in my implant to a computer and sets the loudest and quietest

sound I can hear at each frequency. An advanced degree in Physics, something I do not have, is needed to understand how it all works

Getting used to sound again was a Really Big Adventure! After so many years of deafness my brain took a while to recognise different sounds. I had rehabilitation exercises which my friends did with

me, reading out lists of words or stories while I looked at copies. Then environmental sounds I gradually noticed. The kettle boiling was so loud I was amazed. The clatter of dishes made me very careful doing the washing up!

Outside one day, hanging out washing I could hear a noise and wondered if it was birds. People often said to me how sad that I could not hear birds and I used to think 'that is the least of my problems'. Yet that moment when I called my son out into the garden and he said, "yes that is the birds," I was so excited. Thereafter on our

country walks there was always something to listen to as well as the views and nature around us.

Also the sound of water running, I'd had no idea how loud it could be. Now I could hear a stream or waterfall and enjoy the walks so much more. So useful also to be able to hear when I left a tap running at home.

Back at work I had to get used to a whole new set of sounds. The worst being a

steam distillation apparatus. I said to someone 'how does anyone gets used to all this row, the traffic and everything' and she replied ' you do get used to it'

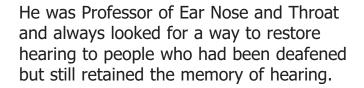
I thought to myself 'a likely story' but now I am just as blasé about it myself.

Music was just a jumble of sound at first but it gradually grew on me. David

always had Classic FM on, and I suddenly realised I was enjoying it. We collected many CDs and went to concerts. Jazz and folk songs were good as well as some opera and classics.

Thus, the implant changed my life completely. So wonderful to be able to talk to strangers who were not easy to lip read. Not to be so dependent on others for help and especially a relief for David not having to 'translate' conversations to me.

The hero of all this is Professor Graeme Clark. Now in his eighties he still works on research at University of Melbourne where he started the first implants in the 1970s.



He got the idea of the implants while he was sitting on a beach playing with a large cochlea shaped shell. Threading a blade of grass through the spiral he thought it would be a way to insert an electrode into the cochlea. This is what has led, with many advances in technology, to the implants we have today, many millions of

> lives changed all over the world. There are some who feel he should get a Nobel Prize. He does have many other awards. From those I know who have met him he is only concerned to help more deaf people. They say he is a lovely man.

The sad thing about all this for me is that before I knew anything about cochlear implants my

The Cochlear Implant itself

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Uncle Laurence in Sydney sent me a newspaper cutting. It was about Graeme Clark and how he had originated the implants after that day on the beach with a cochlea shell and a piece of grass. My uncle was so pleased that there was hope for me. Sadly, not knowing or understanding the medical technology. I wrote back that this would never be any use to me.

How pleased my uncle would have been if he had known what I have now and so proud that it had come from his adopted country.

There is a lot more about Professor Clark in Wikipedia if you are interested.



New research throws doubt on old ideas of how hearing works

The way in which we experience music and speech differs from what has until now been believed. This is the conclusion of a study by researchers at Linköping University, Sweden, and the Oregon Health and Science University, USA. The results have been published in Science Advances, and may make it possible to design better cochlear implants.

We are social creatures. The sound of other people's voices is important for us, and our hearing is directed at experiencing and distinguishing voices and human speech. Sound that arrives at the outer ear is carried by the ear drum to the spiralshaped inner ear, also known as the cochlea. The sensory cells of hearing, outer and inner hair cells, are located in the cochlea. The sound waves cause the "hairs" of the

however, a research team has discovered that this is not the case for sensory cells that process sound with frequencies under 1000 Hz, considered to be low-frequency sound. The vowel sounds in human speech lie in this area.

"Our study shows that many cells in the inner ear react simultaneously to lowfrequency sound. We believe that this makes it easier to experience low-

inner hair cells to bend, sending a signal through the nerves to the brain, which interprets the sound we hear. For the past 100 years, we have believed that



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frequency sounds than would otherwise be the case, since the brain receives information from many sensory cells at the same time," says Anders Fridberger, professor in the Department of Biomedical and Clinical Sciences at Linköping University. The scientists believe that this construction

each sensory cell has its own "optimal frequency" (a measure of the number of sound waves per second). The hair cell responds most strongly to this frequency. This idea means that a sensory cell with an optimal frequency of 1000 Hz would respond much less strongly to sounds with a frequency slightly lower or higher. It has also been assumed that all parts of the cochlea work in the same way. Now, of our hearing system makes it more robust. If some sensory cells are damaged, many others remain that can send nerve impulses to the brain.

It is not only the vowel sounds of human speech that lie in the low-frequency region: many of the sounds that go to make up music also lie here. Middle C on a piano, for example, has a frequency of 262 Hz. These results may eventually be significant for people with severe hearing impairments. The most successful treatment currently available in such cases is a cochlear implant, in which electrodes are placed into the cochlea.

"The design of current cochlear implants is based on the assumption that each electrode should only give nerve stimulation at certain frequencies, in a way that tries to copy what was believed about the function of our hearing system. We suggest that changing the stimulation method at low frequencies will be more similar to the natural stimulation, and the hearing experience of the user should in this way be improved," says Anders Fridberger. The researchers now plan to examine how their new knowledge can be applied in practice. One of the projects they are investigating concerns new methods to stimulate the low-frequency parts of the cochlea.

These results come from experiments on the cochlea of guinea pigs, whose hearing in the low-frequency region is similar to that of humans. This work was funded by U.S. National Institutes of Health and Swedish Research Council.

Story Source:

Materials provided by Linköping University. Original written by Karin Söderlund Leifler. Note: Content may be edited for style and length.

Expedition to darkest Ellesmere Port or a trip back in time!

It's been a long time since we ventured out as a charity to explore, meet up (in real not online) and take that deep breath of freedom to enjoy our great region.



To that end we recently met up at the Ellesmere Port boat museum to go on a guided tour of the whole site out there on the Wirral.

We met in the reception area and proceeded to unwind over a nice cup of coffee after our respective journeys, some from more local areas (Chester, Wigan) and others from Southport and Manchester and even Buxton!

It was a grand day outside and the view from the restaurant across the site was excellent.



The site is at the junction of two canal systems, the Manchester ship canal and the Shropshire Union canal and includes many reminders of how life used to be in the 18th century and beyond. The canal system is still an active working facility although not for commercial use these days and there were vessels large and small for all to see.

To help us in our tour we had our trusty neck loop systems and once I had fitted the tour guide with his microphone (and lots of sellotape to keep it in place) we were ready to set off.





There were of course plenty of Barges to see of all sorts of shapes and sizes, even some made of concrete and it was interesting to note that one of our party had past relatives who used to work on the Thames barges.

The operation of the port was explained and the slip yard where ships were hauled out of the canal for maintenance still had the winding gear to see.



Barges of all shapes and sizes of course



This barge is actually a tug!



And this one is made of concrete...and floats!

Sometimes tours of places can get a little routine shall we say, you know the sort of patter 'On the left we are passing an old wall, on the right is the coal store, in front is a yard Zzzzzzz'

This tour was totally different.

A great example of this was the engine shed with all of the original machinery actually working, rumbling and hissing. It was so fascinating especially as we could see it in full working order that some of us seemed reluctant to move on ;)







All of these machines are looked after by volunteers at the weekend.

On the social history side of the tour we were taken to a row of 'Porters cottages' which had been restored with interiors showing several different ages some of which I remember from my childhood.



All in all, it was a memorable tour and hopefully there will be more over the coming months.





Roaches Restaurant meet up

Anyone who has been part of CICADA for a while knows that our members live all over the North West and beyond, from

Scotland, Cumbria, down to North Wales, the Isle of Man and across into Yorkshire.

With such a widespread distribution of residences it has been difficult at times to provide venues for meeting to attract as many people as possible. Travel can be expensive in the best of times and especially in the present situation.

With that in mind we have decided to



change the aims of meet ups from getting as many people to an event as possible, and



in the process unavoidably excluding some, to having more geographically targeted outings.

After the recent Ellesmere port visit we organized one aimed at members who lived in the Buxton/Stoke-on-Trent area of the country and arranged to meet up at a country restaurant located near a popular hiking and cycling location known as 'The Roaches' which is in the countryside between Leek and Buxton.

With the weather this time of year being at best unpredictable we were keeping our fingers

crossed and were rewarded with a glorious day, which was actually too warm at times outside to be sitting with overcoats on!

It was a chance to meet up with members who have had difficulty getting to places like Liverpool and Preston.

After a refreshing drink outside and a chat we moved indoors for lunch for a more in depth chance to welcome one of our new members who is on the list for an implant shortly.

-We are in the process of organizing more targeted events in other areas, north of Manchester and into Yorkshire so keep an eye out for news on the website.



CICADA support for the local community by Kevin Williams

As well as being involved with CICADA, I have, until the pandemic started, been volunteering at my local hospital. I had various jobs there working in the ENT department and latterly in the Pharmacy, but I also got involved in the training department running sessions for new Nursing and Auxilliary staff talking about deaf awareness. All of which stopped as the pandemic

took hold.



Last year I was asked to run a session for the staff of a care home where one of our members works and recently went back to run another for both the staff and



inmates (oops sorry, Residents!).

The occasion was a day when they were also celebrating Welsh week and so it gave me an opportunity to try a bit of my Welsh with Angharad as well as sampling the Bara

Brith and Welsh cakes.

Some of the audience had hearing issues as well as one who was profoundly deaf but was a first class lipreader and it generated lively discussion afrer the session as well.

Lip reading corner

On 8th October, the Association of Teachers of Lipreading to Adults held their annual conference, in Manchester. I say 'annual' - this was the first one we had been able to hold since 2019. About 40 people attended, from across the UK, despite the train strikes. John Newton represented Cicada, as no one could attend from the National Cochlear Implant Association, and I was really pleased that he was there, and able to share his knowledge of cochlear implants.

There is a shortage of lipreading teachers in some areas, including the North West. We really need more people to come forward to undertake the training. Though the training course is in London, the pandemic has encouraged us to think about different ways of doing things, so about half the course is delivered online. If anyone is interested in training to become a lipreading teacher please feel free to contact me - barbara1810@icloud.com, or go to atlalipreading.org.uk, where there is more information about training to be a lipreading teacher. The enthusiasm in the room confirmed for me what a rewarding opportunity it is.

Notes

As we move towards a new events program, keep an eye open on the website and Facebook pages for more news of events and meet up's. We would welcome any feedback or suggestions for events, articles for Resound especially on your experiences of the lockdown.

Either email secretary@manchestercicada.org.uk

Or write to me at the address below, all submissions are welcome.

CICADA

Website:www.manchestercicada.org.uk

Facebook group: Manchester CICADA club

Secretary direct contact: Text 07533217730

Main contacts for Cicada listed at the bottom of this page.

Manchester Implant Centre

The Richard Ramsden Centre for Auditory Implants,Peter Mount Building, Manchester Royal Infirmary, Oxford Road,Manchester, M13 9WL

Main Contact Details: TeL: 0161 701 6931 (Appointments) TeL: 0161 276 8079 (repairs and spares)

* Please check the website regularly for updates on what the clinic are doing in the light of the virus outbreak.

http://www.manchestercicada.org.uk/implant-clinic/

National Support organisations

British Tinnitus Association: https://www.tinnitus.org.uk/ Hearing Link: https://www.hearinglink.org/ RNID (Action on Hearing Loss): https://www.actiononhearingloss.org.uk/ Disabled Travel Advice: http://www.disabledtraveladvice.co.uk/ Meniere's Society: http://www.menieres.org.uk/ National Deaf Children's Society: http://www.ndcs.org.uk/ National Association of Deafened People (NADP): http:// www.nadp.org.uk/

Equipment Suppliers for Deaf People

Sarabec: https://www.sarabec.com/ Connevans: http://www.connevans.co.uk Hearing Link UK: https://www.hearinglink.org/ RNID (Action on Hearing Loss): https://www.actiononhearingloss.org.uk/

COVID-19 information links.

(Just some official ones which you can subscribe to to get updates)

Main government website whih has links to information and also a facility to be on a mailing list for updates which is handy.

https://www.gov.uk/coronavirus

Most local council websites now have a corona virus section to tell us what they are doing and what services may be affected.

If you need help for other thngs during the duration of the virus then contact social services in the first instance.

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