

For people with Cochlear Implants

Summer 2023

Issue 78



Summer in the Highlands - Eilean Donan castle



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

contents

1. Editorial by Kevin Williams

2. Stepping out in Stepping Hill by John Newton

4. Self repairing hair cells by University of Virginia

6. A trip back in time by Kevin Williams

8. Manchester CI program by Professor Ramsden

10. St George's Hall visit

13. The CICADA runner

15. Notes

Editorial

Welcome to the Summer edition of Resound for 2023.

In this edition we are finally able to report on the social side of the club with two reports on events that have happened recently.

After the COVID lockdowns it has taken a while to gradually get the events schedule going but hopefully this will continue. The next event on the schedule is the visit to the Cheshire Falconry centre coming up in early September and as we organise more events we will be in touch. If you have an idea for a meet up then feel free to get in touch. Just email: secretary@manchestercicada.org.uk or write to the contact address on the back page of the magazine.

After the last issue dealing with accidents and treatments we are pleased to hear from John himself as his recovery continues, and for those of us who have had to spend any time in hospital we can empathise with many of the situations he

1

reports.

Our Patron and founder of CICADA Professor Ramsden has provided an article which reminds us of the great efforts it took to get the Cochlear Implant program going all those years ago and the massive impact that having an implant has had on our lives. It also reminds us all of how long CICADA has been around!

Do visit our website in between issues of Resound as we have regular updates on news, events and links to many helpful websites and organisations.

The link is:

www.manchestercicada.org.uk

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

ps. If anyone would like a full size (A3) print of the painting in this or any past issue please let me know.

STEPPING OUT IN STEPPING HILL by John Newton

For those readers from the further reaches of the North West, Stepping Hill is the name of the large acute hospital which serves Stockport and places nearby including Buxton where I recently earned my entry to that institution by tripping and falling in my yard after a visit to the bins.



This was on a cold evening of 4th May. Transported there swiftly by ambulance I soon learned that my fears were confirmed and I had broken my femur, my shoulder, a tooth and cut my head when it impacted the stone wall.



Not quite four weeks later on the 30th May I was discharged from the hospital into the care of my son and whisked gratefully in his comfortable executive saloon to his house in Worcestershire.

Some one said to me that being in hospital for four weeks must have been a "terrible experience", I am happy to report it was not. I was very lucky of course, the operation to fit a prosthetic joint went smoothly with no complications, the shoulder was left to set on its own. If I stayed still, the pain, calmed by strong medication was bearable (mostly), what I dreaded in the first few days was being moved, to be washed, have my bedlinen changed, being X rayed and so on, that was painful, sometimes shouting-out painful, but thankfully momentary.

It's unfair to criticise the food, given the enormous complication of feeding a hospital full of sick people, it wasn't at all bad, it just wasn't what I wanted to eat and anyway I had minimal appetite, I lost a lot of weight and dreamed about something simple like a soft-boiled egg and soldiers.

The hospital bed is a subject in itself, an amazing device which I guess probably cost as much as a Ford Fiesta with a weird mattress which, to my amazement I discovered was in constant slow movement.

The purpose is to prevent bedsores which all the staff worry about all the time and which makes it acceptable for one to be asked quite frequently "excuse me, but could I have a look at your bottom". Meeting someone at a party, you might have a similar thought, but you wouldn't say it would you?

Being helpless in a hospital bed demands that you will need assistance with some essential functions that you normally like to keep to yourself, and I guess that many people who are there for the first time probably fear the embarrassment of the most. I think I did. And this leads me to the reason why, in spite of these rather less than pleasurable aspects of being in hospital, which I have recounted I conclude that my four weeks were positive and enlightening.

Its the people of course!

Stepping Hill Hospital has about 5000 of them, not all there at once who cost about £300 million pounds a year, Its an astonishing institution although but obviously not at all unique, every major town and city in the UK has at least one such place.

What was a surprise was my discovery of the multinational and multicultural origins

of the workers there at all levels from Consultant to Cleaner. Of course many of them are British born but significant numbers are recent immigrants from all over the world. At one moment I might be attended by an American Physiotherapist on one side of the bed and a nursing sister on the other who has moved here recently from Ukraine.

Actually I found that lying in a hospital bed is a bit like being in a bed in the middle of Piccadilly Railway Station.

During the day the activity is constant, one has a grandstand view of working people, hardworking people actually working, which is an edifying experience which ought to be prescribed for those idiots who tell us that we are a lazy race. However I liked the quiet and dark of the night best, especially as I wasn't sleeping much.

The regular encounters with the nursing sisters coming to check my vitals and give me my medication took place in a little pool of light in the larger darkness which seemed particularly intimate. I was a child again, being cared for by my mother. No wonder everyone falls in love with the nurses (male and female!).

The social skills of the staff which makes it possible to have someone wipe your bottom after using the toilet quite comfortably and while feeling quite unembarrassed is astonishing, but I am not naïve enough not to see the meticulous organisation and training behind it all.

It becomes visible too in the continuous devotion to hygiene and cleaning which is constant, Stepping Hill Hospital is not just a random crew of skilled and loving individual people, it's a well-oiled machine.

As I said earlier, I was lucky, the key to a positive hospital stay is obviously to be getting better and except for the first few days when I worried that I was losing any independence I had, I knew I was (slowly) improving and would walk again. To be getting worse is another ball of string.

I try to imagine what that would feel like because it might happen to me one day. If and when it does, I will consider myself fortunate to live in a society that can run such marvellous places as Stepping Hill Hospital.

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"Hair cells" found in the inner ear, are important both for our ability to hear and our sense of balance. They are known as hair cells because the cells are covered in hair-like structures that serve as mechanical antennas for sound detection. When auditory hair cells are killed, as we learn in school, they are gone for good. But the new UVA Health research shows these delicate cells have the ability to repair themselves from damage caused by loud noises or other forms of stress.

"For many years, auditory research has placed considerable emphasis on the regeneration of sensory hair cells. Although these efforts continue, it is equally important to enhance our comprehension of the intrinsic mechanisms that govern the repair and maintenance of these cells. By gaining a deeper understanding of these inherent repair processes, we can uncover strategies to fortify them effectively. One such approach in the future might involve the utilization of drugs that stimulate repair programs," said researcher Jung-Bum Shin, PhD, of UVA's Department of Neuroscience. "In essence, when replacement of hair cells proves

challenging, the focus shifts towards repairing them instead. This dual strategy of regeneration and repair holds strong potential in advancing treatments for hearing loss and associated conditions."

Hearing Repair

Hair cells are naturally fragile -- they must be delicate so they can sense sound, but they also must withstand the continuous mechanical stress inherent in their jobs.

Prolonged exposure to loud noise harms hair cells in a variety of ways, and one of those is by damaging the cores of the "hairs" themselves. These hair-like structures are known as stereocilia, and Shin's new research shows a process they use to repair themselves.

The hair cells do this by deploying a protein called XIRP2, which has the ability to sense damage to the cores, which are made of a substance called actin. Shin and his team found that XIRP2 first senses damage, then migrates to the damage site and repairs the cores by filling in new actin.

"We are especially excited to have

identified a novel mechanism by which XIRP2 can sense damage-associated distortions of the actin backbone," Shin said. "This is of relevance not only for hair cell research, but the broader cell biology discipline."

The pioneering work has netted Shin and his colleagues more than \$2.3 million from the National Institutes of Health, grant R01DC021176, to

fund additional research into how the cores are repaired. By understanding this, scientists will be better positioned to develop new ways to battle hearing loss -even the kind that comes from aging, the researchers say.

"Age-related hearing loss affects at least a third of all older adults," Shin said. "Understanding and harnessing internal mechanisms by which hair cells counteract wear and tear will be crucial in identifying ways to prevent age-related hearing loss. Furthermore, this knowledge holds potential implications for associated



Hair cells in the Vestibula system

conditions such as Alzheimer's disease and other dementia conditions."

Findings Published

The researchers have published their findings in the scientific journal eLife. The article is open access, meaning it is free to read.

The research team consisted of Elizabeth L. Wagner, Jun-Sub Im, Stefano Sala, Maura I. Nakahata,

Terence E. Imbery, Sihan Li, Daniel Chen, Katherine Nimchuk, Yael Noy, David W. Archer, Wenhao Xu, George Hashisaki, Karen B. Avraham, Patrick W. Oakes and Shin. The researchers have no financial interest in the work.

Story Source:

Materials provided by University of Virginia Health System.

Note: Content may be edited for style and length.

Upcoming event reminder

We are planning to meet up at 11am on 8th September at the Cheshire Falconry Centre to look at the Raptors and then have a bite to eat in the nearby cafe.

If anyone is interested (several have already said they will be coming) drop me an email at secretary@manchestercicada.org.uk. The address is :

Cheshire Falconry Centre, Blakemere Craft Centre, Chester Rd, Sandiway, Northwich CW8 2EB



A trip back in time!

We met recently to take a steam train on the East Lancs Railway line, which runs from Heywood to Rawtenstall with the idea of having lunch at a nearby grill when we got to Rawtenstall. To say the weather was mixed was an understatement alternating from sunshine to short torrential downpours of monsoon quality, however the journey was excellent and very comfortable.





The train arriving at Heywood ready to begin the journey.

The trip from Heywood to Rawtenstall was to be by steam train which brought back memories for all of us. The first issue was that the engine that arrived was now at the wrong end of the train, how were they going to get it to the front then? As smooth as silk the detached engine reversed over some points to the next line then moved forward past the coaches and across another set of points and there it was. All very clever :) Apart from at the stations the main line is a single track.

I was somewhat surprised to see an RAF squadron badge on the side of the engine and also that the type of engine was the Battle of Britain class. For those without a passing knowledge of Burmese the motto reads "Do or Die".



Not sure what the message from Alan was, maybe "watch it's going to shuffle round to the other end of the carriages"? Or "now you see it now you don't"!





All present and correct at Rawtenstall and off to find some food before getting the train back (this one would be a diesel engine).

And lastly, a nice meal before running through the rain to catch the train back!



Manchester Cochlear Implant Programme – the early days

by Professor Richard Ramsden

I was appointed as a consultant ENT Surgeon at Manchester Royal Infirmary in 1972 having finished my training in London. At that time there was the beginnings of interest in the possibility of restoring hearing to individuals with a total sensorineural loss, by inserting an electrical probe into the cochlea.

There were reports coming through from North America and Europe of early success. There was caution in this country and in 1978 a report to the Department of Health and Social Security prepared by 3 eminent British experts following a visit to North American Centres was less than enthusiastic.

Basic research in the UK was undertaken in a number of centres in London, in particular by Graham Fraser at UCH who was working on a single channel extracochlear device that could be produced cheaply. I attended a meeting on the results of single channel devices from a number of American and European centres and was unimpressed by the results.

Nevertheless Graham tried several times to get me involved but it was not until reports started to come in of the much improved results from the multichannel device, in America, Europe and in particular from Graeme Clark in Australia that I began to think there might be something in it. I was also encouraged by Ian Taylor, Professor of Education of the Deaf in Manchester to look into the possible benefits of the multichannel device might be worthwhile.

Around this time in 1987 two things happened about the same time.

I had put out feelers with the Cochlear Company from Sydney and they in turn were very keen to interest me to adopt the technique and invited me to visit Melbourne and Sydney to meet Prof Clark and his team.

Then came a stroke of the sort of good fortune for which every researcher prays. Lawrie Cleary, on whom I had previously carried out successful surgery



Lawrie Cleary and his MBE with Professor Ramsden

for ear infection, became enthused with the idea of cochlear implantation and immediately volunteered to accompany me to Australia. We had the opportunity to question the Clark team in detail and to meet some of their patients.

Also present were the team from Hanover in Germany who were the leading European

implant centre and we were able to question them too about their outcomes. We were most impressed and determined to go ahead with a programme in Manchester.

Money was a problem. Each device cost at that time around $\pm 15,000$ and when the costs of employing supporting staff was computed we reckoned that the whole implant



Marilyn Graham with the professor

package cost around £40,000. There was no central funding at that time for what was perceived as an experimental procedure. Lawrie therefore set up a charity, HEAR, to raise enough money to get us started, to purchase the first few devices and pay the salaries of the new staff that we needed.

Our Audiology team at MRI had a database of patients with a profound hearing loss and we began the process of assessing candidates who might be suitable for a cochlear implant.

Ian Taylor allowed us rooms for assessment and rehabilitation in his department in the Ellis Llwyd Jones building.

Our first patient was Marilyn Graham a 41 year old postlingually deafened grandmother from Cumbria. There was a certain mixture of excitement and anxiety the day of the operation. A colleague from the Hanover programme, Roland Laszig, had come to make sure I didn't make a mess of it – which I'm

glad to say I didn't. All went well and Marilyn went home for the month long wait for the switch on.

When that day came there was a pervasive air of anxious anticipation; for Marilyn, for our implant team, for the team from Cochlear and for me...would it work?!!

We had no need to worry. Tuning was supervised by Sue Roberts from Cochlear and then the moment for switch on arrived. Almost immediately Marilyn asked "is there someone in the room from Australia?" She had recognised Sue's accent. We knew then it had worked. In fact straight away we could converse easily with Marilyn.

There was not a dry eye in the house.

The story hit the national headlines. Marilyn became hot property. The press, radio and television clamoured for an interview with her and she performed very movingly about being able to speak with her grandchild for the first time. She was front page news on the Sunday Times and was a star. I too was interviewed several times and was invited to appear on the Terry Wogan show, but much as I admired Terry Wogan, I turned it down, not wanting to appear to be commercialising the operation at what was still early days.

We implanted several other patients with the funding from HEAR. Other centres in the

UK soon followed suit, again tapping into charitable funds. Eventually sufficient data were available to enable the MRC Institute of Hearing Research at the University of Nottingham to produce the Sommerville and Marshall analysis for the Department of Health detailing the costs, benefits and candidature issues.

On the strength of that report, in 1995 David Mellor announced the approval of central funding for Cochlear Implantation for adults with a profound hearing loss. That was an occasion for great rejoicing and led to the establishment of a small number of designated properly funded implant centres throughout the UK.

The rest, as they say, is history.

HEAR eventually raised in the region of $\pounds 2$ million and financed a number of deafness related organisations and implant related research projects. When I retired the balance of the charity's funds was donated to Manchester Royal infimary to help establish the new Implant Centre.

St Georges Hall Minton tiles reveal

During the week of 14th August several CICADA members and their friends went to St. George's Hall in Liverpool to see close up, the huge tiled floor, which is normally covered up to help preserve it, being revealed in all its glory.

Small groups of us went to see the tiles over several days rather than usually going in one group, but of course we have collaborated on the things we saw, so here are the gathered images of the week with thanks to Dian Pollitt, Lynne Grimshaw and my able on site film producer Mr A. Corcoran esq.

We also produced a video which has been posted on the CICADA Facebook site and will be uploaded to the website in due course....



On a visit a few years ago the floor was covered in wooden tiles.



All this was hidden from view for years.



Two views of the magnificent hall with around 30,000 tiles and a floor length in excess of 700 feet.





There are lots of different aspects of the design work, on the right the nearest circle has the Red Rose of England, the next one has the Liver Bird in the middle and subsequent ones have been the Scottish Thistle and the Irish Shamrock. As you would expect from a hugely important port city, the theme of the tiles is of a maritime nature.

The floor was covered in 1860 to provide a hard wearing surface for dancing and this is only the tenth time it has been uncovered.





A close up of the part of the floor with the Liver Bird towards the centre of the whole floor.



Members visited the display in relays over a period of several days during the exhibition week.



Having viewed the tiles some people then wandered all over Liverpool from the Library to the Cavern disrupting the locals!





The CICADA runner

Fun Muddy run at Warrington 11th June 2023

More intrepid action from Lynn raising money for Breast Cancer research

Another month and another run completed although looking at the photos it looks more like the aftermath of an assault course!



This is the list of events that Lynn will be taking part in:

- *30th August 2023,* Trinity Hospice Night run 7.5K at Blackpool
- *24th September 2023,* 10K run at Runthrough event at Warrington.
- *13th October 2023*, 10k Night Shine Walk, Manchester
- *21st October 2023*, 10K run at Tatton Park, Knutsford
- *26th May 2024*, Half Marathon run at AJ Bell, Greater Manchester run 2024

I assume she'll be taking Christmas off!! (Ed)

Lip reading corner



Barbara

In our lipreading classes, we don't just practise lipreading, we pass on information about things that might be helpful. Recently we talked about the Hidden Disabilities Sunflower Scheme.



Allison



With this scheme, you can order a lanyard, and identification card, which indicates to staff in shops, on transport, and in public spaces, that you may need some extra help.

(You can see me wearing mine in the St George's Hall photo).

This has now been extended to cars. For people with a hearing loss, if you break down, or have an accident in your car, communication can become very difficult. You can now order a free sunflower sticker or car magnet, to show any roadside and emergency services that you have a hidden disability. They can then ask about the support you need to keep you safe.

You can order one free car symbol from https://hiddendisabilitiesstore.com/nationalhighways.

You have to complete a registration form. I found it needed some persistence to find the right process, but once I succeeded, the badge came quickly. It is now displayed on the back of my car.



National Highways also say that if you need assistance on the road, and can't use the phone, you can contact them via text, on 0738 028 3600 for roadside assistance.

This information was taken from the magazine of the National Association of Deafened People (NADP).

Barbara Hitchins

19.8.23

Jeannette Auld 10th July 1931 - 29th July 2023

We are sorry to report the passing of Jeanette Auld recently whose funeral has been held in Bromborough.

Jeannette was one of four sisters all of whom were Cochlear Implant recipients, Jeannette and Irene had their implant in Manchester, another



sister in Liverpool and the remaining sister in Australia where she now lives.



As a long time member of CICADA, Jeanette was a regular attendee at events that we held in Liverpool such as the visit to the Maritime museum and Christmas dinners at the Liner Hotel.

On behalf of all at CICADA we would like to pass on our condolences to Jeannette's family.

Notes

We would welcome any feedback or suggestions for events, articles for Resound especially if you have been through a situation and have come through it and have knowledge that might help others.

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/

Accessory help

The accessory help page has links to videos about how to connect your processor to different accessories, such as remote microphones, TV support etc. that may be supplied to you by the implant centre. Also if anyone is going into hospital and wants one of the Hearing support cards to show staff how you prefer to communicate then please let me know.

If you have printing facilities then the card is in PDF format at this link at the bottom of the page:

https://www.manchestercicada.org.uk/accessory-help/

If you need a laminated copy write to me or email at the link below.

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15