

For people with Cochlear Implants

Winter 2017

Issue 53



"Kinder Downfall in the Peak District"



a charity supporting implant patients

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

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Editorial

Welcome to the winter edition of Resound.

Now that we are in the new year we can look back on an eventful time certainly as far as CICADA is concerned.

There have been some notable firsts, the coach trip, boat trip and lunch to the Lake District for example and finally managing to get a conducted tour around St George's hall after the disappointment of last year.

There have been varied types of event as well such as the tour around Elizabeth Gaskell House in Manchester and the Ring Of Bells meal and trip around the Lewis Carroll centre in Daresbury.

We welcome all the new members who have joined this year and are featuring an interview with one of the recent joiners in this issue.

CICADA is continuing to work closely with the Implant team at the MRI and their request for volunteers to help out at the drop in communications sessions is a reflection of this (and could prove useful to the volunteers as well!)

Once again, if you have a story to tell about your journey with the Implant program or an everyday occurrence we would love to hear from you, this magazine after all is about you.

The Conference and AGM is approaching fast so do pencil it on the calendar, more details will be coming to you shortly.

All of us on the EC thank you all for your continued support throughout the year and look forward to seeing you at an event or meeting soon.

Kevin Williams Editor

CICADA Xmas meal 2016

by Kevin Williams

This years Christmas meal was held at the Liner Hotel in Liverpool at the end of November. It's the first time we have been there for a meeting and were very pleased with the service and facilities, so pleased that we will be back in March for our AGM.



We met up in the specially reserved bar to have a chat before the lunch

There was plenty of time for a good chat with friends, including the three sisters see if you can spot them!





Our own private dining room which was well laid out and there was plenty of room for us to mingle among the mince pies



A good time was had by all





a real Merry Christmas!



Severe dizziness treated with steroid injectons into the eardrum.

Injections of steroid into the ear are an effective treatment for a common form of severe dizziness, suggests a new study.

In a new trial, scientists from Imperial College London compared current treatments for Meniere's disease, which causes debilitating dizzy spells.

They found that injections of the steroid methylprednisolone, through the ear drum, are as effective as the current 'gold standard' treatment. The current option is an antibiotic called gentamicin, and is also injected into the ear, where it destroys inner ear cells.

The treatment prevents dizziness attacks, but can leave patients with permanent hearing damage.

The new trial, published in the Lancet, found that the steroid injections are as effective as gentamicin, but without the side effects. Patients who received the steroid injections were better at hearing speech clearly, compared to those who received the gentamicin injections.

The researchers are now recommending medics offer the steroid injections to patients before trying gentamicin.

Professor Adolfo Bronstein, lead author on the paper from the Department of Medicine at Imperial, said: "Meniere's disease causes disabling attacks of dizziness that in some cases can leave people unable to work. However at the moment the only treatment we have for severe cases is a so-called 'destructive treatment' that kill cells in the inner ear. Doctors, including ourselves, always assumed steroid injections were less effective than the current treatment, but we were surprised to see they work just as well as gentamicin, but do much less harm." Meniere's disease affects around 30,000 people in the UK, and causes intense attacks of dizziness that last anything from a few minutes to 24 hours. During the attacks a person is usually unable to stand, and suffers from hearing loss, as well as nausea or even vomiting. The condition usually strikes people over 40, though scientists still do not know what triggers the disease. One theory is that the condition causes a build-up of salt and fluid in the inner ear.

This section of the ear, which is closest to the brain, holds equipment crucial to maintaining balance. This equipment constantly communicates with the brain, eyes and limbs to keep us on our feet.

Scientists believe the build-up of pressure can cause tiny leaks of fluid in the inner ear, which can cause the balance equipment to malfunction. The condition can also lead to permanent hearing loss.

There is no cure, although the early stages of the disease can be treated with medication and exercises. Severe cases can be treated with injections of gentamicin. After being injected into the ear, the medicine travels to the inner ear where it destroys the cells responsible for balance, and stops the dizzy spells. Usually only one ear is affected, therefore patients still have a working balance mechanism in their healthy ear, and can re-train their balance with exercises.

However, gentamicin can also destroy hearing cells, and up to one in five patients can be left with permanent hearing loss.

In the latest study, researchers at Imperial gave 60 patients with severe Meniere's disease either injections of gentamicin or steroids. The patients were on average having more than one dizziness attack a week. They were given two injections of one of the treatments, under local anaesthetic, two weeks apart. Neither the patient nor the researcher knew whether a patient received steroid or the gentamicin.

After a two year period, all patients' dizziness attacks had reduced by around 90 per cent. However the patients who received the steroid injections had better speech discrimination -- the ability to hear words clearly -- than those who received gentamicin.

Neither treatments were found to have any other side effects, although the injections of gentamicin often triggered a severe dizziness attack when first administered.

Professor Bronstein added that those who received steroid injections were more likely to need additional jabs to stop their dizzy spells.

"For a patient who lives in a remote location where accessing repeat injections would be difficult, then gentamicin would be an option. However, if a patient is able to receive repeat injections, and is concerned about future hearing loss, the steroid injections may be a better choice."

Natasha Harrington-Benton, Director of the Meniere's Society, who funded the research said: "We are pleased to have been able to support this research and are encouraged by the outcome. The trial has led to a better understanding of gentamicin and steroid treatments for Meniere's disease; giving hope to those affected by this complex condition."

Story Source:

Materials provided by Imperial College London. Original written by Kate Wighton. Note: Content may be edited for style and length.

Blogger to raise money for Hearing Link through e-book sales



Blogger and Hearing Link supporter Laura Lowles is to raise money for our charity through the publication of her first e-book. Laura, a cochlear implant recipient, started her blog 'The Invisible Disability & Me' in 2014 which shares her experiences of hearing loss and her journey to receiving a cochlear implant.

Inspired by her blog posts, Laura has now penned her first e-book, named after her blog.

The e-book covers topics such as tinnitus, hearing loss in the workplace, travel and cochlear implants, offering tips and hints on how to cope with hearing loss on a daily basis. Laura also writes about her personal story and shares the advice she has received along the way.

To help publish the book digitally and in hard copy, Laura is calling on her blog readers and supporters to back her Kickstarter crowd funding campaign. To find out more, visit her blog.

Once printed, proceeds from sales of the book will be donated to our charity as a token of appreciation for the support we have given to Laura and her family. To support Laura's efforts, visit: https://www.kickstarter.com/projects/55907 2881/hearing-loss-and-cochlear-implantself-help-ebook

Turn an Ear to Hear -Research at Cardiff University

by Norah Clewes

I took part in a project 3 years ago, at Cardiff University. It was conducted by Jacques Grange and John Culling, of the School of Psychology.

It was intended to find how CI users can best hear in noisy situations.

realistic simulation of a real restaurant in Cardiff, to demonstrate the impact of reverberation.

The result summed up was that the best listening strategy is to turn the good ear (cochlear implant) slightly towards the



speaker whilst still being able to lip-read the speaker.

Sitting as far away as possible from kitchen and loudspeakers and other sources of noise is also advised. Personally, if there is loud music playing I have no compunction in asking the staff to turn it down (or off altogether!) The researchers are now involved in further work to see what can help CI users hearing in noise.

Tests were made in a sound-treated room with a range of loudspeakers giving speech and background noise from different directions. All those taking part were matched with a hearing person of roughly same age so comparison could be made.

A test involving young-adult hearing participants was later performed as a highly Full details of the research are on Cardiff University, School of Psychology Website. It is called "Turn an Ear to Hear"

Many thanks to researcher Jacques Grange for passing on the results of the project to all the participants.

Norah Clewes

Thermal Cameras Help to Reduce the Invasiveness of Cochlear Implant Surgery

Impaired hearing is something that we usually associate with elderly people. However, many newborns are also confronted with hearing problems or are born deaf. In many of these cases, a normal hearing aid does not help and hearing patients are obliged to resort to socalled cochlear implants in order to be able to lead a normal life.



These implants must be inserted into the cochlea through elaborate and very invasive surgery. Thermal imaging cameras from FLIR Systems have helped to make this process less invasive and thus much safer for the patient.

Cochlear implants are a wonderful achievement of modern medicine and have already helped many patients who are profoundly deaf or severely hard of hearing. The implant is surgically placed under the skin behind the ear. However, this technique requires highly trained surgeons and is not without risks. A surgical implant procedure may result in injury to the facial nerve, meningitis, tinnitus, infections, cerebrospinal fluid leakage and many other afflictions.

Less Invasive Surgery

Researchers have been looking into making cochlear implant surgery less invasive. In a collaborative effort by the Swiss ARTORG Center of Biomedical Engineering Research and the Institute of Surgical Technologies and Biomechanics of the University of Bern

as well as the University Hospital Inselspital of Bern, researchers have been working on an image-guided surgical robot system, which is able to drill a small tunnel hole in the skull behind the ear through which the cochlear implant can be inserted.

The new procedure is much less invasive than conventional techniques and allows for rapid recovery and minimum hospital stay time. The surgery is preceded by a CT scan of the head, a thorough computer-based planning of the drilling trajectory and a semi-automatic segmentation of important anatomical

features. For the actual surgery, the acquired information then needs to be synchronised with the patient. The surgical robot requires a drilling depth of approximately 25 mm. Through innovative processes and a sophisticated security concept, the deviation from the planned end point can be kept below 0.2 mm, which reduces the risk of facial nerve damage significantly.

Monitor Drilling Temperature

"During the drilling process, there is another risk that we need to take into account," says Arne Feldmann, Biomechanics researcher and doctoral student at the University of Bern. "There is also the danger of degenerating the facial nerve solely by the drilling temperature, as the drilling trajectory is typically within a 0.5 mm range of the nerve. That is why it is very important to keep the drilling temperature below a critical threshold."

The optimisation of this drilling process was the subject of a detailed pre-study conducted at the University of Bern. A purpose-built test rig was constructed in order to measure the temperature increase in the skull as a result of the drilling process. The entire process, for which cow bones were used, was monitored in detail by means of a FLIR thermal imaging camera and a load cell was used to measure drilling forces and torques. The researchers opted for a FLIR A655sc science-grade LWIR camera with a 50 um close-up lens.

Affordable Research and Science Thermal Imaging

"It was very important for us to obtain a detailed thermal view of the bone structure, because we wanted to know exactly what happens during the drilling process in terms of temperature at any drilling depth," said Arne Feldmann. "The area we were interested in is only about 10 mm in width and 30 mm in length. We were able to study this small window very accurately with the thermal camera. For a camera which is that affordable, the A655sc offered us a high level of image quality."

With its uncooled detector, high resolution, and all of the cutting-edge functionality scientists and researchers have come to expect from FLIR, the A655sc brings affordable research and science thermal imaging and measurement to a whole new level. Combined with FLIR's dedicated thermal analysis software, researchers have a powerful set of tools that allow them to achieve good results quickly.

"The test set-up would not have been

successful without FLIR's ResearchIR thermal analysis software," Arne Feldmann continued. "We used ResearchIR to record



the thermal video and to thoroughly analyse the results, including plotting out maximum temperatures and monitoring a number of critical points."

Optimising the Drilling Process

"The results obtained from our experiments with the help of the FLIR A655sc have allowed us to define an optimised drilling process," said Arne Feldmann. "With the new minimally invasive and robot-based approach, safer, more gentle and less invasive cochlear implant surgery will be possible in the future."

Thermal images acquired during the test set-up allowed researchers to compare standard drill bits with innovative, newly designed surgical drill bits. The patented new drill bit design clearly presented a significant temperature reduction during the drilling process. The FLIR A655sc thermal imaging camera was also used to compare the temperature impact of different cooling and irrigation strategies. Furthermore, researchers discovered lower temperatures with a stepwise, interval based drilling procedure, as opposed to continuous drilling.





Evidence of 'hidden hearing loss' in college-age human subjects

Researchers from Massachusetts Eye and Ear have, for the first time, linked symptoms of difficulty understanding speech in noisy environments with evidence of cochlear synaptopathy, a condition known as "hidden hearing loss," in collegeage human subjects with normal hearing sensitivity.

In a study of young adults who may regularly overexpose their ears to loud sounds, a research team led by Stéphane Maison, Ph.D., showed a significant correlation between performance on a speech-in-noise test and an electrophysiological measure of the health of the auditory nerve. The team also saw significantly better scores on both tests among subjects who regularly wore hearing protection when exposed to loud sounds. Their findings were published online today in PLOS ONE.

"While hearing sensitivity and the ability to understand speech in quiet environments were the same across all subjects, we saw reduced responses from the auditory nerve in participants exposed to noise on a regular basis and, as expected, that loss was matched with difficulties understanding speech in noisy and reverberating environments," said Dr. Maison, an investigator in the Eaton-Peabody Laboratories at Mass. Eye and Ear and Assistant Professor of Otolaryngology at Harvard Medical School.

Hearing loss, which affects an estimated 48 million Americans, can be caused by noise or aging and typically arises from damage to the sensory cells of the inner ear (or cochlea), which convert sounds into electrical signals, and/or the auditory nerve fibers that transmit those signals to the brain. It is traditionally diagnosed by elevation in the sound level required to hear a brief tone, as revealed on an audiogram, the gold standard test of hearing sensitivity.

"Hidden hearing loss," on the other hand, refers to synaptopathy, or damage to the connections between the auditory nerve fibers and the sensory cells, a type of damage which happens well before the loss of the sensory cells themselves. Loss of these connections likely contributes to difficulties understanding speech in challenging listening environments, and may also be important in the generation of tinnitus (ringing in the ears) and/or hyperacusis (increased sensitivity to sound). Hidden hearing loss cannot be measured using the standard audiogram; thus, the Mass. Eye and Ear researchers set out to develop more sensitive measures that can also test for cochlear synaptopathy.

Diagnostic measures for hidden hearing loss are important because they help us see the full extent of noise-induced damage to the inner ear. Better measurement tools will also be important in the assessment of future therapies to repair the nerve damage in the inner ear. Mass. Eye and Ear researchers have shown in animal models that, under some conditions, connections between the sensory cells and the auditory nerve can be successfully restored using growth factors, such as neurotrophins.

"Establishing a reliable diagnosis of hidden hearing loss is key to progress in understanding inner ear disease," said Dr. Maison. "Not only may this change the way patients are tested in clinic, but it also opens the door to new research, including understanding the mechanisms underlying a number of hearing impairments such as tinnitus and hyperacusis."

Authors on the PLOS ONE paper include Dr. Maison, M. Charles Liberman, Ph.D. of the Eaton-Peabody Laboratories of Mass. Eye and Ear, and Michael J. Epstein, Ph.D., and Sandra S. Cleveland, Au.D., CCC-A, of Northeastern University. Research supported by NIDCD RO1 DC00188 and NIDCD P30 DC 05209.

Story Source:

Materials provided by Massachusetts Eye and Ear Infirmary.

FCC Adopts Rules to Facilitate Transition from TTYs to Real-Time Text Technology

In a historical open meeting, the Federal Communications Commission (FCC)



adopted rules to facilitate a transition from text telephony (TTY) technology to real-time text (RTT) technology on December 15, 2016. In the Report and

Order, the FCC:

• Permits wireless service providers and handset manufacturers to support RTT in lieu of TTY technology

• Ensures RTT users will be able to call 911 for emergency services and 711 for relay services

• Defines RTT to be interoperable across networks and devices and backward compatible with TTYs and

• Establishes a phased rollout of RTT for wireless networks from December 31, 2017 to June 2021.

In the accompanying Further Notice of Proposed Rule making (FNPRM), the FCC seeks comment on:

• A timeline to sunset its requirement for RTT to be backward compatible with TTY;

• Integration of RTT into

telecommunications relay service operations, and

• Real-time text features that may be needed for people with cognitive disabilities and people who are deaf-blind.

(The FCC will announce the public

comment due dates for the FNPRM when these become available.)

Claude Stout, TDI Executive Director shares with TDI members:

"Last Thursday's formal action for Real Time Text Technology (RTT) by the fivemember Federal Communications Commission was historic, in terms of impact and system change for many Americans who will benefit enormously from using this direct mode of communication every day over the IP networks. This technology will not just benefit Americans who are deaf and hard of hearing, but their hearing family members, friends, colleagues in the workplace, service providers, and others. This will help provide an additional kind of accommodations that we can use with our hearing peers in any life activity area, such as education, employment, human services, civics, leisure and recreation, commerce, transportation, and etc. Those who are deaf and hard of hearing will feel more included and independent in the general community.

We give our deepest gratitude to all parties in government, industry, academia, and consumer advocacy for making possible this communication tool for its effective deployment in the marketplace. We look forward to working with all parties to see to that this technology reaches its full promise and potential as a mainstream benefit for everyone involved."

(Real Time Text - for more details see back page.)

Ten Minute interview - Mandy Saunders



A chance to chat to Mandy Saunders a new CICADA member from the Manchester area.

Mandy (on the right) with her colleague Amanda Howard

Q - Can you tell me a little bit about yourself, and what you do?

A - I was born deaf and wore 2 hearing aids all my life starting with the body aids and then onto behind the ear type during my teens. I could not hear fully with my hearing aids and could not hear a sound when I took them out. I am now in my early fifties (mind you!)

I am married and have one son who is in his final year at secondary school and am employed as a Technical officer with a Local Authority.

As part of my role I go out in to the community in my area to assess people who have hearing loss varying from mild to profound.

I also promote Deaf Awareness training to staff or anyone who may meet or work with Deaf people/children, promote and offer information about our services and network with Technical Officers around the North West.

At present we are supporting deaf people to apply for Personal Independence Payment (PIP) which is very time consuming.

Q - How long did you have a hearing problem before going for the implant?

A - All my life really, I was born deaf, and wore 2 hearing aids, originally with the body aids which were big and bulky then wore behind the ear hearing aids when I was in my teens and have struggled until my fifties.

Q - How did the hearing problems affect your work?

A - All my working life I have had to rely on lipreading and could not hear many sounds including environmental sounds, people shouting at me and myself not hearing them (looks like I'm ignoring them when I am not)

When I am in a meeting and assessing it can be difficult when meeting those from an ethnic

minority as they can be difficult to lipread when I don't have a sign language interpreter with me (I use Access to Work funding for my support needs).

I use both sign language and speech to communicate.

Q- How long did it take for you to get to get on to the implant program?

A - I was referred by my GP in January 2015, saw the consultant at the implant centre at MRI in July 2015 then a couple of operation dates were set then cancelled due to priority of other cases.

Q - How long is it since your operation?

A - It's been just over six months, I was switched on at the end of June.

Q - How have you been since the operation, are you getting used to the new device?

A - The operation itself was successful and went smoothly. When I was switched on, it was horrendous, and I was very upset in front of Deborah. The sound was very robotic and not clear. I remember going home with my sister in law and the sirens going off it was scary and hurting me.

I ended up going back 2 days afterwards for counseling and ongoing support and had the device turned down as I was still upset about it. I couldn't cope with the sounds at first, it took me a long time and it was certainly not what I expected.

I continued to have support and the device altered. I now tune it to the level I am comfortable with which is not as high as the highest setting as I cannot cope with that. I still cannot use the telephone or catch words as the consultant told me before surgery

Q - Has the cochlear implant changed your hearing?

A - It has improved for example I am picking up new sounds which I have not heard before and I remember hearing a noise in the kitchen, it was bugging me and eventually when my husband came home he told me it was the fridge! Now I block it off and it doesn't bother me.

I do feel that it does not replace my hearing aids and the best thing to come out of it is to be able to hear noises louder around me, as for many years I kept asking my local hearing aid centre to make it stronger and louder they could not do due to my type of deafness.

I cannot listen to music very well as the voices are not coming through and I have tried to listen to my favorite music from my college days (80's) and have a long way to go yet. I don't listen to it in the car, when others put the radio on I tend to take the implant off as I cannot concentrate with the terrible boom-boom etc.

Q - What do your colleagues think about it?

A - All of my colleagues have been very supportive.

Q - How have your family been with the operation and the rehabilitation?

A - Very supportive, they were worried about the operation of course with it being near the nerve etc. and really did not want me to have it as I have managed for 50 years. Q - How did you find out about CICADA?

A - I asked the implant Centre for any support groups.

Volunteer Equipment Officer

Central Manchester University Hospitals

Audiology Department - MRI

We have opened up our Assistive Listening Devices (ALDs) room for drop in sessions for patients/the public to come in and try out the equipment.

ALDs can help people with a hearing loss hear better in challenging situations e.g. at work, in a restaurant or bar, in meetings, in

a lecture hall, listening to music or the television, hearing on the phone or mobile etc.

We have a small pool of volunteers who show the devices to people who drop-in and help them to try them out.

Volunteers work in pairs. The drop-in is open every Monday (except Bank Holidays) 2 – 4pm. We are looking for new volunteers to join the team.

What

skills/qualities/commitment are we looking for?

• We are looking for people who can communicate well with a range of people who have a hearing loss.

• We are looking for good interpersonal skills.

• Volunteers need to be competent with using/learning about new technology.

• Volunteers need to have a sufficient level of manual

dexterity in order to use and demonstrate the equipment.

• We are looking for volunteers who are age 18+

• We are looking for volunteers with good time keeping and who are reliable.

• We would want volunteers who can attend for at least a 2 hour session at



least once a month.

What can we offer you?

• A Central Manchester NHS Trust volunteers' uniform (red shirt) and Trust ID badge.

• Training in use of the equipment.

• An enjoyable and satisfying role in helping our patients to hear better in challenging situations.

What we would expect from you?

- To attend the 1 day Central Manchester NHS Trust induction training.
- To attend a half day generic Central Manchester NHS Trust volunteer training.
- To attend the Audiology department fire,

health and safety, and manual handling training etc. as appropriate.

- To sign a volunteer agreement.
- To wear the volunteers' uniform and ID badge at all times when engaged in voluntary work at the Trust.

All applicants will have an interview to assess their suitability for this role.

Please do contact me if you have any questions or would like me to send you an application form for the role.

Karen Smith Hearing Therapist Email:karen.smith@cmft.nhs.uk Telephone: 0161 276 6302



StageText at the Oldham Coliseum

Oldham Coliseum Theatre provides access information for its Disabled audiences here:

http://www.coliseum.org.uk/about-us/access/

If you're a first time attender at Oldham Coliseum Theatre, there's also full information on parking, public transport and where to get a coffee or have a meal in Oldham here:

http://www.coliseum.org.uk/about-us/

The theatre's BSL (British Sign Language) interpreted and captioned performances for February – July 2017 are listed below. Oldham Coliseum Theatre will announce its Autumn-Winter 2017/2018 performances on its website on Tuesday 27 June 2017.

Gaslight

An Oldham Coliseum Theatre Production Friday 3 – Saturday 18 February At Oldham Coliseum Theatre Tickets £14.50 – £22.50

Newly wed Bella Manningham is convinced that she is losing her mind, just as her mother did before her. But is it really all in her head, or is there something more sinister afoot? BSL interpreted performance date is Wednesday 15 February 2017, 7.30pm

Meat Pie, Sausage Roll

An Oldham Coliseum Theatre Production Friday 3 – Saturday 25 March At Oldham Coliseum Theatre Tickets £14.50 – £22.50

Amanda's dad is a simple man; there are three things Mick really cares about in this world – his family, his mates and the mighty Oldham Athletic. But when Amanda's wedding falls on the last day of the season, Mick finds his loyalties torn, and on top of that Asif, her future husband, hates football!

From the team behind 2015's smash-hit, Dreamers, Meat Pie, Sausage Roll is a new musical set against Latics' memorable 1990/1991 season.

BSL interpreted performance date is Wednesday 15 March 2017, 7.30pm Captioned performance by StageText is

Saturday 18 March 2017, 2.30pm

Spring and Port Wine

An Oldham Coliseum Theatre Production Thursday 13 – Saturday 29 April At Oldham Coliseum Theatre Tickets £14.50 – £22.40

Tyrannical father Rafe Crompton struggles against his three children as they long to join the Swinging Sixties. Spring and Port Wine was written by Bolton playwright Bill Naughton who wrote Alfie and All In Good Time, filmed as The Family Way. BSL interpreted performance date is Friday

28 April 2017, 7.30pm

Hard Times

An Oldham Coliseum Theatre Production Friday 19 May – Saturday 3 June At Oldham Coliseum Theatre Tickets £14.50 – £22.50

It's Charles Dickens as you've never seen him before in Stephen Jeffreys' fast-moving adaptation of the classic novel.

Set in a northern mill town, Hard Times

follows mill owner Josiah Bounderby and schoolmaster Thomas Gradgrind, and the effects their actions have on their friends, families and employees.

BSL interpreted performance date is Friday 26 May 2017, 7.30pm

The Father

An Oldham Coliseum Theatre Production Friday 16 June – Saturday 1 July At Oldham Coliseum Theatre Tickets £14.50 – £22.50

Andre once had a wonderful career as a tap dancer and now lives in Paris with his daughter and her husband. Or was he an engineer whose daughter now lives in London? The trouble is, he can't quite remember. This funny and moving play portrays the devastating impact of dementia on one man and the people in his life.

BSL interpreted performance date is Friday 30 June 2017, 7.30pm Captioned performance by StageText is

Saturday 1 July 2017, 2.30pm

Music and the Deaf

The very title of the charity Music and the Deaf may seem a contradiction in terms. But, according to Danny Lane, the Chief Executive Officer of the Yorkshire-based prevent young people from having music in their lives. Danny himself is living proof that it's more than possible for someone with profound hearing loss to become an

organisation, that's only because there's still a misconception that people with hearing loss can't be musical.

As he explains: "There needs to be a lot more awareness of what deaf people can achieve. There

needs to be more expectations that deaf people can access, play and enjoy music." And this is what Music and the Deaf aims to do – break down the barriers that



accomplished musician and derive huge pleasure from listening to music. He was encouraged by enlightened parents to join his brother in playing a brass instrument while still at school. He also learned to

play the piano and took a GCSE in music that led, ultimately, to him studying for a degree in French and music at Keele University in Staffordshire. "I wouldn't be able to communicate with confidence if it wasn't for music," he says. "Music is not just about listening or creating sound, it's about sharing creative ideas, communicating with others and celebrating the achievement of performance." Today he stands at the helm of the ground-breaking musical charity that was founded by Huddersfield's well-known deaf organist Dr Paul Whittaker OBE, who stepped down in

2015 after 27 years. It's Danny's role to continue Paul's pioneering work and he's been busy doing just that by overseeing two major new projects. He first seeks to showcase exactly what deaf musicians are capable of. To that end Music and the Deaf, which is now based in Halifax but works nationally, has formed a quartet of talented players, including Danny himself, who are staging performances around the UK. Known as the FORTE Ensemble, it has been funded by the Arts

Council. Danny plays the piano alongside flautist Ruth Montgomery, trumpet and corner player Sean Chandler and violinist Eloise Garland, who also sings. "We were not seeing deaf musicians performing," says Danny, "so we thought it was time to do something about it. I knew all of the musicians but we didn't really perform together until last year. This year we played at the House of Lords, which was amazing. Our concerts attract both deaf and hearing audiences."

While there's no reason why a hearingassisted musician can't achieve high musical standards, Danny says too few are being encouraged to think about becoming a professional and there are still prejudices at work. He knows of one young deaf musician who hid her disability in order to gain a place at a conservatoire. "She was struggling to get into a conservatoire so didn't mention her deafness; they should be judged on their musical abilities only," he added. While Danny wears what he describes as "an old-fashioned analogue hearing aid", because digital hearing aids affect his ability to play music, he still



needs the services of an interpreter in his day-today work. Sign language interpreter Sheryl Gale, who says she trained after realising the communication problems deaf people face, now travels with him as he tours schools and community groups around the country. Danny works directly with deaf youngsters as well as

training teachers and running workshops. The organisation also has a network of freelance trainers. Much of his work is in mainstream schools, where there might be only

one or two deaf children, and he will run workshops for both hearing and deaf children together.

The second major project undertaken by Music and the Deaf in the past year has been to join forces with Huddersfield University to look at ways in which rapidly advancing digital technology can be harnessed to help deaf people access music. Frequalise, as it is known, worked with local schools and allowed hard of hearing children to experiment with computer software and music apps on tablets and phones. "Technology is revolutionising the way we live," says Danny, "and it's so adaptable. There are high quality music apps, some of them free or low cost, that can be used. We have explored a range of different things. One thing we did find was that singing was quite popular. Even if someone is deaf they want to be like their pop idol and use a microphone." The project's findings, which were shared at a seminar in Huddersfield last month, could, he says, change the way deaf children and young people are educated. At the core of Danny's work is the belief that there's no reason why deaf children shouldn't be given a musical education. As he says: "In some schools they are excluded from music lessons and I believe passionately that's removing choice. It's important that children don't miss out on any subject." Music and the Deaf has made the UK a trailblazer but Danny says there are signs that other countries are starting to sit up and take notice: "We went to Australia last year on a tour and we found that there were no music programmes in schools for deaf young people but some were planning to set them up. We have had requests to go to America, Portugal and Canada next year, so there is a growing interest."

> Source:Huddersfield Daily Examiner www.examiner.co.uk"

Plucky Eleanor wins MED-EL UK 2016 Music Grant



With drum rolls and trumpet calls at the ready, MED-EL is pleased to announce that the under 19s 2016 MED-EL UK Music Grant winner is... Eleanor Thompson from Brayton, Selby in North Yorkshire.

This music-loving, MED-EL cochlear implant user has chosen to learn the guitar, which struck just the right chord with the judging panel.

Eight year old Eleanor has already faced great challenges in her short life: she was born prematurely, weighing a mere 1lb 4 oz., and her early months were a battle for survival. Although her hearing loss was diagnosed at an early stage, due to her fragile health Eleanor was unable to undergo cochlear implant surgery until she was 3 and half years old.

In recent years, Eleanor has enjoyed attending music workshops run by Music and the Deaf through a local charity, Lollipop. She hopes that her guitar lessons will let her spend many happy hours strumming along with her peers.

As our under 19s music grant winner Eleanor receives a musical instrument up to the value of \pounds 500, and a 30 minute lesson per week for one year, plus a \pounds 30 allowance for sheet music.

Cassandra Brown, Managing Director of MED-EL UK states: "Music appeals to people of all ages and MED-EL is proud to support music appreciation for our users both through our technology and initiatives like the Music Grants. We wish Eleanor lots of fun with her guitar."

For more information about the MED-EL UK Music grant visit www.medel.com/uk/info/.

Making NICE

by John Newton

CICADA has recently been asked for their views on the current policy for prescribing cochlear implants which is set by NICE.

It's a body which usually makes the news when they refuse to allow the use by the NHS of some life extending but expensive drug. They are (now) The National Institute for Care Excellence, they change their name from time to time but rather cleverly manage to keep the same acronym.

They were originally the National Institute of Clinical Excellence. They are a government body who take their instructions directly from the secretary of state and quite independent of the NHS.

Whatever their name they have the daunting job of ensuring that the money spent on the health service is spent sensibly and, probably more important, fairly. Daunting because of course, the money is always limited so they have to make choices, the sort of choices which most of us hope never to have to make like "what is a life worth (in money I mean)?" or "what is the value of being free from pain?" or, in our case "what is the value of being able to hear better?".

As every schoolboy knows (or at least everyone who hosts a cochlear implant) NICE decided in 2009 that the NHS would fit cochlear implants. Before that funding was not automatic and had to be hustled for in each case. They made their views known by issuing a document which is called a "guideline" but which practically speaking is accepted by the NHS as gospel.

Before that date implantations were counted in hundreds, with the intervening years they now number thousands, it's a few years since the Manchester clinic hosted a party to celebrate their 1000th implant and they are just one of several clinics around the country. Very broadly they said that if you were deaf and not getting any benefit from conventional hearing aids you would be considered for a cochlear implant. If you like to have all the detail you can read the 2009 document here

https://www.nice.org.uk/guidance/ta166

The British Cochlear Implant Group (BCIG) is the body representing the clinical professionals involved with cochlear implants. They set the standard for the detail of how the NHS carries out the recommendations of NICE.

You can read that too here:http://www.bcig.org.uk/wpcontent/uploads/2016/05/BCIG-Quality-Standard-2016.pdf.

The BCIG is currently considering an approach to NICE asking for a review of the 2009 Guidelines (and I am finally getting to the point of this article!). They have asked CICADA for their views about that and we have told them that, in general we have confidence in the way the CI clinic interpret the guidelines and the BCIG standards.

When NICE review their policy we hope that they will look again at the policy of limiting adults to just one CI.

When the original guidelines were produced NICE admitted that the evidence available about the benefits were limited because of course the number of implantations done then was fairly small. Now there are thousands with a CI and therefore much more evidence available of the benefits and we hope that NICE will be persuaded that this evidence deserves to be looked at systematically.

NICE's responsibility, remember, is to decide on whether the benefits justify the cost. Those of us who have had our lives turned around by this marvellous device don't need persuading but the people who manage the money, (our money) have to make these difficult choices.

We have no idea what the outcome will be or indeed how long it will take but we keep our fingers crossed. JSN 170117

What is Real Time Text ?

Real-time text (RTT) is text transmitted instantly as it is typed or created.

Recipients can immediately read the message while it is being written, without waiting.

Real-time text is used for conversational text, in collaboration, and in live captioning. Technologies include TDD/TTY devices for the

deaf.

Use by the deaf

Real-time text is frequently used by the deaf, including in IP-Relay services and TDD/TTY devices.

Real-time text allows the other person to read immediately, without waiting for the sender to finish composing his or her

sentence/message.

This allows conversational use of text, much like a hearing person can listen to someone speaking in real-time.

Also live captioning for TV, a feature enhancement in instant messaging, captioning for telephony/video teleconferencing, telecommunications relay services including ip-relay, transcription services including Remote CART, TypeWell, collaborative text editing, streaming text applications, next-generation emergency services.

And Finally ..

Notes for the Diary.

Annual Conference and AGM Saturday 18th March at the Liner Hotel in Liverpool. Full details will be sent out to all members soon.

Lunch at the Italian Orchard in Preston. The return of an old favourite February 25th 12:00 for 12:30 details to be sent out soon.

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

editor@manchestercicada.org.uk

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A big thank you to contributors to this issue, Norah Clewes, Mandy Saunders and John Newton.

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