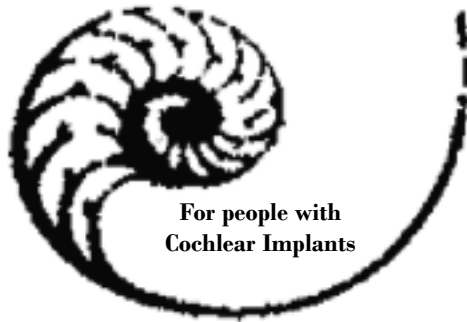


ReSound

MANCHESTER COCHLEAR IMPLANT NEWSLETTER



For people with
Cochlear Implants

Summer 2011

Issue 39



Caldon canal walk



This newsletter has been produced on behalf of the
Manchester Auditory Implant Centre, the Cicada Club and the HEAR Charity

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Editorial

Cicada club now has a new chairman (see below) although Norah Clewes is still a much valued committee member.

Do you fancy a canal walk returning on a steam train then see page 3 forthcoming events.

We have been updating our website recently and the new version will be going live on the 1st July 2011. The web address will be the same as it is now <http://www.manchestercicada.org.uk> and from here you can link to our Facebook and Twitter site.

Take a moment to have a look and maybe join our Facebook group. If you are going to facebook directly the link is:-

<http://www.facebook.com/group.php?gid=103424809721314>

To get to the twitter account type <http://twitter.com/#!/Manccicada>

Hedy Williams Editor

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Cicada Club's new Chairman

We have been busy over the last few months with visits to Martin Mere Wildfowl trust, the annual Bowls competition and the AGM which was held at the Manchester Conference Centre amongst other things.

The highlight of the AGM was a presentation by Mr Kevin Green the lead surgeon at the Manchester Implant Centre, a full report of which is included in this issue. The conference was attended by delegates from as far away as Cumbria and Wales as well as those closer to Manchester and was a great opportunity to catch up with friends and club members over lunch.

I wish to extend my thanks to the

members, the Committee and the Hon. Secretary for all the hard work that has gone into organising the recent events and my personal thanks to Norah Clewes whom I took over from as Chairman. Norah continues to serve on the committee and is an invaluable source of knowledge on the mysteries of the Club's operations.

Work continues on the development of the Facebook page which you are all welcome to contribute to, and we will shortly be re-launching the website which is undergoing a refresh.

Did you know we have a twitter account as well? Full details of all the links are included in this

issue, so if you have issues, concerns or queries, or would like to join in the discussions, get in touch.

We are looking to be able to organise more club events focussed on the younger implantees and their parents. If you would like more information or have any ideas for social and other events for the younger end of the membership please let us know. Cicada Club is free to join and members pay an annual subscription from as little as £6 and is open to **all** cochlear implant patients.

Kevin Williams
Chairman

A chance encounter - Tim Barlow

I was having a cuppa with a book outside the cafe on Tooting Common last week when some hippy-looking bloke asked if he could sit at my table. Sure, why not? Going back to the book I heard him comment on it - "Zen, eh?" I have never encouraged casual conversations with strangers because I could never hear what they were saying; and struggling to understand was too much hassle. But now with my implant I can hear so I acknowledged him. A conversation gradually grew until we ended up chatting for two hours! Unbelievable.

He turned out to be an Iraqi who was brought up in Afghanistan. We exchanged life stories. He had long hair, straggly goatee beard, piercing eyes and a hooked nose. It would have been quite an alarming aspect but for the smiling eyes. The conversation was fascinating. He told me how strange it was growing up in Afghanistan in the sixties when suddenly strange-looking Englishmen started arriving with long hair, smoking dope and wearing Afghan coats. Bit like the locals I opined? I asked him if he was a Muslim but he said he was under Buddhist instruction. He said he liked coming to the Common to get under the trees and feel transported to somewhere else. He'd like to live in the country but felt that in a small community he would be questioned and regarded with suspicion, whereas in cosmopolitan London he is not.

I bought us both tea and cakes during the conversation, while he made no offer to help. I'm sure he would have done but simply couldn't afford it. He has a daughter to look after during the week, he said. She goes home to her mum in Norwood for weekends. He mentioned that he normally doesn't come to cafe on the Common because he has to watch the pennies. He hadn't bought himself a tea when he came to sit down at my table. Maybe he doesn't get to talk to that many people in daily life? Certainly it was me who had to bring the chat to an end because I was due to go out to a meeting that evening. When he left he walked all the way back with me to the top of my road despite having a bicycle. I think the conversation was nourishing for us both. So a CI really makes the world go round, and is changing my life in remarkable ways.

Helmets and Cochlear Implants

By Norah Clewes

Extracted from an interview with Ginny Kanka in Network, journal of the National Association of Deafened People:

"My husband is a keen motorbike rider. With thanks to my cochlear implant I can now hear whilst on the back. Pre cochlear implant I had to take off my hearing aids before putting on the helmet else feedback whistling would be screeching at my husband (not myself as, at that time, I could not hear them). After the implant, I spent hours carefully taking apart my helmet. With a friend, we cautiously chiseled out a small lump accommodating the area where the magnet coil rests. It is marvelous to hear the pitter-patter of rain on the helmet!"

During the email 'chats', Ginny added that "cyclist helmets are different ... the shell is perforated with holes or gaps (for sweat to dry out) it's a case of trying on different bicycle helmets till one with gap/hole fits perfectly over the CI 'lump' is found."

"The builder hard hat is normally not lined with various padding as a motorbike helmet is; I guess a large 'rubber polo-sweet ring' needs to be stuck inside the hard hat, positioned to fit over the

magnet."

I investigated further and found this - Cochlear web site support centre (<http://www.cochlearamericas.com/Support/2235.aspx>) which suggests a thin "sweat band" to place around the forehead and over the coil and the top of the processor or microphone to hold the external processor and magnet in place under a helmet. Cochlear also say it is not a good idea to physically alter a helmet as this might compromise the safety of the helmet. However, Ginny does not think she has done so with her motorcycle helmet.

Children with cochlear implants and helmets

Ginny also suggested some web sites with comments on helmets for children with cochlear implants.

One comment said these days many helmets come with an adjustable tightener in the back, so fitting them for a cochlear implant user is easier (and the child can loosen it before putting it on and then tighten it up.) A good bike shop should be able to help you and your child find a helmet that fits well without modification. A thirteen year old wrote she used a thin sweatband, which helped to keep the external parts from falling off.

Many useful comments are found on the Internet - just google "cochlear implant and helmet".



TROUBLESHOOTING

User-friendly, useful advice at the click of a mouse!
Web-based User Support from MED-EL on www.medel.com

Nobody likes problems, but everyone appreciates a speedy solution and that is why MED-EL are proud to announce the addition of a troubleshooting section to their new look website.

The troubleshooting pages can be found in the "User Support" area of the website, this section is indicated by a white and red life buoy.

Easy to use

For ease of use troubleshooting is divided into different categories of problem:

- Processor malfunction
- FineTuner
- Using audio devices
- Something is broken
- None of the above

- Quickguide
- Sound quality issues

Navigating the help provided is very straightforward. You are guided through the advice and information by clicking on a "yes" or "no" button in response to step by step questions. Animated sequences and videos demonstrate procedures such as how to replace batteries, change a cable or replace an earhook.

Time-saving

As its name suggests, the quickguide is designed to save you time. This one page flowchart diagram will indicate the correct pages of the Opus 2 Processor manual you should consult to find the answers to your queries.

Introduction to the Opus 2

The troubleshooting section also includes a series of videos which will familiarise you with the workings of your Opus 2 processor. This includes an introduction to the different parts of the processor, switching on and off, disassembling the processor, the Fine Tuner, DaCapo System and the Baby BTE.

Customer Service

MED-EL hope that you will find the troubleshooting section on the website useful and time-saving. However, should your problem remain unresolved, please contact your clinic.

forthcoming events

Canal Walk

This planned walk is along the Caldon Canal Staffordshire, (www.waterscape.com/canals-and-rivers/caldon-canal) from Cheddleton to Froghall.

For most of the way, the canal is adjacent to the Churnet Valley Railway (www.churnet-valley-railway.co.uk) which runs steam trains most weekends in the summer between Cheddleton and Froghall, including the weekend of 10 July.

We will return from Froghall to Cheddleton by steam train.

The walk begins in Cheddleton, on the A520 Leek to Stone road, between Leek and Cellarhead.

If you wish to participate on this event please contact the club secretary email below.

No pre-payment is required for this event

however if you plan to attend please contact me at Jonathan Salas, 5, Lander Close, Old Hall. Warrington. WA5 9PJ or by email at secretary@manchestercicada.org.uk

Family (including children of course) and friends are most welcome.

Lunch at Southport

Monday 12th September Lunch, meeting at 11:00am at the 'Prince of Wales Hotel' Lord Street Southport, PR8 1JS, Tel 0871 222 0039 contact Norah Clewes 48 Queens Road Chester CH3 5HB or by email at nwclewes@cix.co.uk

The 3 course carvery lunch with choices including vegetarian, plus tea/coffee cost £8. The hotel has it's own parking and is a 10 minute walk from the train station.

Jonathan Salas opened the meeting by thanking everyone for attending and said how fortunate we were to have Mr Kevin Green, the primary surgeon at the MRI, here to speak with us.

KEVIN GREEN: began by saying that he had been asked to the meeting as since 2003; the last time he attended, there had been lots of developments at Manchester. The most significant thing was that there was now a new 'young' surgical team consisting of Ian Bruce, Simon Freeman and Simon Lloyd. He said that Professor Ramsden is (semi!) retired but still does some cochlear and brainstem implants for patients who can't have a Cochlear Implant. Because we now do many types of implants (cochlear, brainstem, middle ear and bone anchored), the team decided to change the name of the clinic to the 'Manchester Auditory Implant Centre'. Another development at the clinic that there have been over fifty bilateral implants carried out on children following guidance from N.I.C.E. and this is becoming the norm. It is however, not normally the case that adults automatically get a bilateral implant and most bilateral implants are part of trials run by Implant Companies; however it is felt that in time this will change. The results so far for all the centres around the UK that are doing bilateral implants in children are very good. Both ears are implanted during the same operation and it usually takes three to five hours to complete. This is a great advance on twenty years ago when it took this long

to do one operation.

ALISON COOKSON: then said that one of her friends had been offered a 'bi-aural implant'. Mr Green replied that this is called a Neurolec system, which is used in France and involves putting an implant in one ear and tunnelling under the scalp to put an electrode in the other ear. The Manchester clinic don't use this technique and are not planning to do so at the moment.

ALISON COOKSON: said her friend was still thinking about what type of implant to go for.

KEVIN GREEN: They were doing a lot of implants on people who still had some hearing, using the implant to help with the higher frequency hearing loss and allowing the ear to use the remaining natural hearing for picking up lower frequencies. The advantage of this was that it saved existing hearing in patients of this type. The situation of having quite a lot of residual lower frequency hearing was quite common in adolescents and in younger patients. In the past putting an implant in usually destroyed any residual hearing that was there. This technique also has the benefit of being able to work in patients who also have a hearing aid so improving hearing in noisy backgrounds and also helping to hear music better. Preserving the inner ear structure - especially in six to seven year olds - may allow future treatments to be carried out. This work was being looked at by other centres around Europe as the UK and in particular Manchester was a leading centre

for this type of operation.

The general term for this type of implant was EAS or Electrical Auditory Stimulation, a combination of electrical stimulation from the implant and auditory from the normal hearing or hearing-aid.

JONATHAN SALAS: then asked how the electrodes were detected in a high frequency condition. Mr Green replied that studies were being carried out at the moment to look at the results of the new types of implant. With the experience gained in the first fifty bilateral implants on children operating times have reduced significantly although no one can quite match Professor Ramsden's phenomenal speed! Mr Green said that they are at the stage now with bilateral implants where they think PCT's will be willing to pay for more adults as part of the trials especially when someone has a short history of deafness. They have also had one occasion where the fitting of an implant cured someone who had been suffering with extreme tinnitus in one ear but who had normal hearing in the other. Work in Europe along these lines has also proved extremely successful. This contrasts dramatically from 1988 when a patient had to have no hearing at



Kevin Green and Alan Corcoran Hon Treasurer of Cicada club

all to qualify for an implant.

It is becoming increasingly recognised that to hear in noisy environments you need two ears regardless of whether one ear has an implant and the other has something else, after all most people who wear glasses have two lenses and not a monocle! So that is where a lot of the research is taking place at the moment, assessing the effect of residual hearing when an implant is used. It is hoped that the result of this research will mean more people will be offered implants.

JONATHAN SALAS: then asked whether partial implants were any cheaper than the full implant. Mr Green replied that it was just as expensive and in the long run may be more expensive as more implants may be done.

JAMES RYLANCE: asked when the first successful middle ear implants were carried out? Mr Green said December 2008 - just over two years ago.

ALAN CORCORAN: asked if the cochlear had to be working. Mr Green said that some hearing was required and the operation boosted it. However it was now getting more complicated with all the different scenarios that were available.

BILL ALLEN: Asked if the middle ear implant is like a booster increasing the vibrations does this automatically assume the hair cells in the cochlear have to be in good working order? Mr Green replied that some hearing was needed and would require a hearing test to be done for a profound loss; he would be carrying out his 20th operation like this in two years on Monday.

JAMES RYLANCE: contrasted his experience with an ENT surgeon where nothing could be done for him with the vastly different situation today.

‘Mr Green said that in the UK we have become more progressive in our approach to dealing with disabled people as a whole but this has only improved gradually over the last 20 years or so.’

MARION LEEMING: said she had been single-sided deaf since the age of 7 and was advised to live with it so the help offered to children like that these days was fantastic.

Mr Green replied that was the way it used to be and that may still happen in some clinics.

SANDRA FLETCHER: asked why hearing music was so difficult. Mr Green explained that as good as cochlear implants were they could never compare to the ear itself for its ability to distinguish pitch which is why it was important to preserve as much natural hearing as possible. This lack of pitch sensitivity in implants made it more difficult to understand languages such as Chinese where pitch was an important part of the language which is why the combined approach would improve things dramatically.

BILL ALLEN: said he was aware that MED-EL were working on trying to improve the implants in this area although Mr Green thought that it would still not be as good as natural hearing. Mr Green replied that he thinks it will improve to a certain extent but he doesn't think it will ever be as good as having that low pitched normal hearing which makes a big difference but he does think it is going to improve.

ALISON COOKSON: said she still uses a hearing aid in one ear which helped with low frequencies would cochlear implants improve in this area?

Mr Green said he thought there would be some improvement but that more focus would be put on preservation of the existing hearing. Mr Green said that some patients were able to wear a cochlear implant and a hearing aid in the same ear if it was needed.

STEVEN GUNN-RUSSELL: asked if

Manchester was going to continue to give patients the choice as to which make of implant and if so was there any information on which was the best one to use.

Mr Green replied that there was no evidence of one being better than another and that the clinic was in the middle of tendering for the new preferred supplier which may reduce the choice to two types, one of which would be a normal type of cochlear implant and the other aimed at hearing preservation. The clinical freedom that the clinic has allows the best choice to be made for the patient.

ALAN CORCORAN: said the patient wouldn't probably know what was best anyway.

Mr Green said he had a personal preference but that increasing the range of choices for a patient resulted in a lack of negotiation strength with the manufacturers and with 160 – 170 implants a year being carried out at a cost of two and a half million pounds any money that could be saved was welcome.

NORAH CLEWES: asked about totally implantable implants as a friend of hers had lost his processor while sailing! Mr Green said that there had been a few of these in Australia but the disadvantage was the increase in body noise picked up by the implant. Another big issue with them was the microphone, where does it go and how long would the batteries last as this

would mean an operation to change them. In five or ten year's time when technology had improved, especially battery life would be better.

BILL ALLEN: said that when he heard about the Neurolec idea of feeding a microphone over the other side of the head he thought that bi-lateral hearing would be available at a cheaper cost but had since revised his thoughts especially regarding sound location.

JONATHAN SALAS: said he had read several years ago about a babel fish that would fit in the ear and translate languages are they still around?

Mr Green asked where you could get one as it would be very useful!

JONATHAN SALAS: commented that in the UK we have become more progressive in our approach to dealing with disabled people as a whole but this has only improved gradually over the last 20 years or so.

Mr Green agreed saying that hearing loss was the great unrecognised disability.

MARION LEEMING: asked whether the implant restricted how good a processor you could have.

Mr Green replied that all

companies had taken the decision to ensure that all new external processors would be backward compatible. The only reason to replace an implant would be if it failed.

ALISON COOKSON: asked about the age expectancy of the implant.

Mr Green replied that no one really knew, however they had been doing implants for twenty-three years without age problems and expected at least thirty years of life. As far as age is concerned the youngest patient implanted by Professor Ramsden was six months old and the oldest he had operated on was ninety-two years old!

ALAN CORCORAN: asked if there was a particular level of hearing for a decision on a middle ear implant.

Mr Green replied that you would need to be wearing a hearing aid or a BAHA and there is a range of loss to be considered to make the decision.

JAMES RYLANCE: asked if you still get post operative balance problems?

Mr Green replied that was the case because you are going into the inner ear and the inner ear does balance as well as hearing although the problem was less

with hearing preservation surgery because it's less traumatic.

JAMES RYLANCE: asked if it was always a temporary loss?

Mr Green replied that in the majority of cases it was quite common to be unsteady for a week or two.

ALAN CORCORAN: asked if it was correct that a child's cochlea stays the same size as they grow?

Mr Green replied that was correct, the cochlear was fully formed at birth and doesn't change in size so there is enough give in the electrodes to allow for growth of a child's head and wouldn't need to be replaced because of child's growth.

GEOFF BROWN: asked if there was anyone looking at restoring a sense of balance in the same way as restoring hearing?

Mr Green replied that a research group in Los Angeles have started to do vestibular (or balance) implants in the same way as cochlear implants but it was still in the early stages of development.

At this point the meeting was closed by the club secretary who thanked Mr Green for an interesting and valuable talk.



Introducing the Vibrant Soundbridge

Now suitable for Children

The Vibrant Soundbridge is an alternative to conventional hearing aids and offers an innovative method to overcome hearing loss for adults and children with mild to severe sensorineural hearing loss or conductive and mixed hearing losses. However, unlike a hearing aid which amplifies sounds, the Vibrant Soundbridge converts sound

into mechanical vibrations.

How does it work?

The Vibrant Soundbridge directly stimulates middle ear structures in much the same way as normal sound moves via the ear canal. This "direct drive" stimulation enables excellent sound quality without blocking the ear canal.

Discreet audio processor

It consists of an external and an internal part. The external part is an audio processor and is worn on the head. The internal part is an implant which mechanically vibrates the middle ear structures. The audio processor is available in different colours.

Natural sound quality

The Vibrant Soundbridge offers improved hearing quality and speech understanding, particularly in noisy surroundings. Users describe the sound

quality as more natural, including the sound of their own voice. Many users report that they are able to hear softer, high frequency sounds, such as children's voices and birds singing.

Suitable for children

The Vibrant Soundbridge is the only middle ear implant that is attached only to the structure of the middle ear which it is stimulating. This makes the Vibrant Soundbridge independent of skull growth and therefore suitable for implantation in children.

The Vibrant Soundbridge received EU market approval for implantation in children and adolescents in June 2009.

For more information about the Vibrant Soundbridge visit www.medel.com click on implant solutions or contact office@medel.co.uk.

*The **First Paediatric Vibrant Soundbridge Middle Ear Implant case was televised on ITV1 on Friday 11th March at 20:00 on Children's Hospital at Manchester Royal Infirmary.***

NICE CONFERENCE BIRMINGHAM 10th MAY 2011

The chairman was one **PHIL HAMMOND "GP, Broadcaster and journalist"** whom I have never heard of but a rival to Tigger in energy. Interesting that in his opening remarks he stressed the importance of patient involvement, a theme which recurred so much during the two days that I almost believed that they meant it. He was also at pains to say that there must be rationing which, of course is what NICE is all about.

Professor Sir Michael Rawlins is chairman of NICE and clearly highly respected by the delegates the majority whom were clinicians of various kinds working in the NHS, not a group to hero worship yet at the end of the conference they gave him a standing ovation (he is retiring from the job apparently). He reviewed what NICE had done since it was set up and reiterated its mission, reminded us that their remit now includes Social Care saying that the new Health & Social Care Bill "defines the new NICE".

Professor Sir Bruce Keogh is NHS Medical Director at the Department of Health (DoH) stuck closely to Newton's Law of Platitudes, although I suppose, to be fair, it is good that the bosses say things like "empower patients", "enhance the quality of life" (for patients with long term conditions i.e. us) "positive patient experience".

With the appearance of **Dr Clare Gerada chair of the Royal College of General Practitioners** ("as seen on TV" the day before) I felt we were getting into the real world. Her points were that quality is incompatible with the "chaos" that's going on at the moment. (discreet cheer from at least one delegate). She felt that we must "embrace modern technology for access to GPs" (ditto).

Cynthia Bower id chief executive of the Care Quality Commission (CQC). Amongst other things she said that many providers are not compliant with the standards that CQC set. She explained that the

normal NICE approach to standards for drugs and clinical procedures is not necessarily appropriate for social care. For one thing they never concern themselves with staffing levels. She stressed the importance of a holistic approach declaring that much of the feedback they get shows that kindness is sometimes more important than technology. **Integration** of health and social care seems to be widely accepted as good and inevitable. And this of course has particular relevance to hearing loss.

In the discussion which followed this section **Dr Gerada** was inspired to declare that GPs should not be described as private providers they are "salaried to the state". (Trustees will be aware that handing over commissioning to GPs has been described as "privatisation" which had obviously upset Dr Gerada). The chairman declared "we need whistle blowers because things will always happen"! On the question of **competition** (between providers that is) Professor Keogh claimed that NHS acute hospitals are often more competitive than private providers. There was a general concern expressed in various ways throughout the conference that reorganisation and GP commissioning was a different issue to the current reductions in hospital funding which could negate any benefit which organisational changes might bring, (might!)

After coffee it got a bit more interesting. **Dr Fergus Macbeth**, a NICE Director involved with clinical practice introduced the candidates for **Shared Learning Awards**, three Doctors who each described the work they had done in raising standards in their own areas. This was specific stuff about the real world and very interesting. None of it with any connection with hearing loss, so I do not give any details here, they can be found on the NICE website via the bold words above.

There were about 30 **exhibitors** to see in between

plenary sessions but mostly technical stuff concerned with medical devices, none relevant to hearing loss. From the NICE stand I picked up hard copies of recent publications about audiology which I will report on when I can find time to read them.

There was a choice in the afternoon of four “streams” of which I chose to devote my attention to **“No decision about me without me-Patient-centred care”** I stuck with this mostly out of consideration to my STTR helpers for whom dodging from room to room would be awkward and also because it was chaired by **Victoria Thomas** who runs the patient and public involvement part of NICE, her remit includes **Patients Involved with NICE (PIN)** and she was instrumental in getting NICE to pay my expenses and the STTRs. She even met me at the start and was generally very hospitable.

Sue Ziebland from **Oxford University** started off the afternoon session by describing the qualitative research she leads into health care. This means collecting patient’s narratives rather like the “Hidden Voices” project which Hearing Link and The British Library did and which several of us were involved in. The results of Ms Ziebland’s work are published on the web as a resource for learning, training and discussion. The emphasis is on the problems of younger people. The video clips she showed as examples had no subtitles but of course I had my attendant STTRs. I thought this session was very interesting because it is deliberately “unscientific” but instead concentrates on real world experiences. She asserts that such stories are a much more powerful engine of change than are dry statistics and I think she is right. If you want to really understand the impact of deafness “Hidden Voices” is more effective than pages of numbers.

Paul Streets is Director of Patient and Public Involvement at NICE and Victoria Thomas’s boss. He talked about the benefits of patient involvement and claimed they are legion. There is a lot of hard evidence that **patient involvement leads to all sorts of real improvements**. Patients who are involved in their own care and understand it have better outcomes, get better quicker and even cost the NHS less. This is I believe a **rallying call** at all patient groups including ourselves. We have no need to feel shy because of our lack of technical knowledge, we can be confident that our opinions

‘Patients who are involved in their own care and understand it have better outcomes, get better quicker and even cost the NHS less. This is I believe a rallying call at all patient groups including ourselves ’

and experiences are a valuable resource to NICE. In the discussion which followed this point was emphasised by various people from NICE committees actually pleading for more patient input to their deliberations.

This message was emphasised by **Kasey Chan** from the

Dept of Health who described various initiatives to promote consumer views within the **Care Quality Commission (CQC)**. She also emphasised that the proposed regional **Health and Wellbeing Boards** are intended to have a large element of consumer championing (if there is such a word).

This session was concluded by **Frederico Moscogiuri** who works for the charity **Arthritis Care**. He described some examples of how patient involvement worked in practice in this area. He related how volunteers, themselves sufferers were trained to counsel others, a notion which resonated into our own sphere of hearing loss. I have undergone such training by Hearing Link as have other NADP members. Mr Moscogiuri claimed this policy to be very effective.

The last sessions of the day served to illustrate and emphasise this theme of the benefits of patient involvement but got a bit technical at times. **Sally Crowe** described some of the nuts and bolts of getting patients input to research for example. **Sarah Buckland** and **Sir Nick Partridge** explained **INVOLVE** an organisation which was set up by the DoH specifically to promote public involvement in health and social care, see <http://www.invo.org.uk/Questions.asp> **Dr Sophie Staniszewska** of Warwick University discussed the nature of “patient evidence” and again emphasised its importance claiming it to be equal to “scientific” data.

Susan Ringwood chief executive of BEAT stood in for **Barbara Mcloughlin** who is chair of PIN and could not attend (she is also of course CEO of the RNIB and an absolute charmer). Ms Ringwood explained what PIN does reiterating the message of the importance, acknowledged enthusiastically by NICE people, of the patient output.

Here endeth the first lesson.

Day two started with “Working well together” with **Dr Carole Longson** of NICE, **Patrick Vallance** of GlaxoSmithKline and **Mark Wilkinson** from the NHS. It seemed mainly a chance for all to say nice

things about the relationship of the NHS with big pharma. A positive blizzard of platitudes and no one unkind enough to mention that big pharma exists to make money for its shareholders. Mr Vallance stressed the vast cost of developing new drugs (well he would wouldn't he?). The one figure which stuck in my notebook was that there are only about 90 separate drugs on the market catering for about 7000 identified diseases.

Next **Chris Ham CEO of The King's Fund** and **Professor Peter Littlejohns** of NICE talked about **Improving NHS Productivity**. This was quite an interesting session. What emerged from it is that the NHS cost £100 billion a year (as any fool knows) and there are lots of opportunities for improving productivity. Moreover he claimed that many of the initiatives towards greater productivity also improved clinical outcomes. (I suppose it's only fairly obvious that if people get better quicker, they cost less). What particularly resonated with me was his claim that "integrated care", for "chronic conditions" e.g. hearing loss, was a major factor in improving productivity. Professor Littlejohn was concerned about the variation in standards and productivity around the country where the best can be 3 times as productive as the worse. He was also worried that the proposals in the new bill could lead to greater fragmentation, rather than more integration.

Dr Gillian Leng is deputy CEO of NICE. She talked about the ways in which NICE guidance and evidences, or will be disseminated. This means primarily to doctors and nurses but also to patients. She referred to **NHS Evidence** which is an information service mostly accessed via the Internet or internet nets but which she proposed to also make available via smart phones and to "syndicate" to "third party systems". (does this mean like Wikipedia? I don't know). She described a concept called "Pathways" which bring together all the relevant evidence and guidance about a particular condition and I wondered if there in one for hearing loss.

In the next session **Professor Littlejohns**, joined with **Professor Nancy Devlin of the Office for Health Economics** and **Dr Richard Cookson from the University of York** to talk about the ways in which the drama and trauma of disease, disability and death are reduced to mathematical formulae, a necessary but to many a distasteful task. Most will have heard of NICE's primary measure "Quality of Life Years" (QUALYS) but we learned that there are various initiatives to improve and refine this measure, particularly to give the patients view more voice. Dr Cookson is concerned with measuring happiness and explained, not surprisingly that it is difficult to pin down. He

preferred a measure of "Capability" but it got very technical at this point and my notes are illegible but I wish I had written down the 10 factors which he defined as measuring "Capability".

The first afternoon session was **Demonstrating the value of new technologies** and I sat down eagerly, expecting some reference to hearing loss. Alas, the session was almost entirely concerned with **diagnostic devices** and much of it about matters of no interest to anyone outside NICE. I had time to reflect that NICE is clearly not the leader in hearing loss technology, in the philosophical sense, which prompted the question who is?

The final session of the conference was on **Value Based Pricing** and I wondered why this subject had attracted so much attention. For one thing it only applies after 2014 and only to **new drugs**, which appear very rarely. I don't know why so much ink and breath has been spent on the topic, most people, even within the NHS will notice no difference. The only vaguely interesting comment on it was made by **Professor Karl Claxton of York University** who pointed out that the drugs market was distorted in the sense that there was a single buyer and, in the case of a new patented drug, a monopoly supplier. Normal market forces were therefore suspended.

*(Purely as an aside here, an interesting dilemma was revealed over new **Antibiotics**. What doctors want is to have a new antibiotic on the shelf, available but not used, so that when the old drug becomes ineffective, as they all do eventually (bacteria being clever little beggars) the new drug can be brought into play. But the manufacturers want to make their money before the patent runs out after 10 years so they want the drug to be used as much as possible. Various solutions were proposed.)*

The final address was made by **Earl Howe, Parliamentary under Secretary of State in the Department of Health**. Mostly platitudes as you would expect but he did say that NICE's status in the future would be more secure and "not subject to the whim of the Secretary of State". He also reminded us that their remit now covers social care. He cleverly managed to make no reference to the huge controversy which has been seething away for weeks now over the new Bill and as received politely but not enthusiastically by the delegates.

John Newton



your letters



Norah and Dave Clewes

Letter to the Editor

I would like to thank the Cicada committee and all the members for their support over the last few years whilst I have been Chairman. Thank you all for the present of lovely miniature roses at the AGM and the chocolates for Dave who has always been a great support to me (and I had my share of the chocolates too!)

I am very pleased that Kevin is now taking over and I know he will make sure the club thrives and supports all Manchester Cochlear Implant users in the future. As I am still a committee member I hope I can also continue to work for Cicada as much as possible.

I must add, congratulations to you for the production, and thanks to HEAR Charity for the funding, of the new all-colour ReSound. It is really attractive and easy to read magazine of which that we are all very proud.

Best wishes
Norah Clewes

The Cornerhouse Cinema

Last Sunday, as my 67th Birthday gift from my eldest daughter, I got taken out to see a film called "My Dog Tulip". It is cleverly scripted, an animated hand-drawn comic-strip story, with excellent 'dog psychology', so comes highly recommended for those who like to have dogs as pets!

However, the point of this is more to do with using your CI on 'T'. My daughter arranged everything, however, I was taken aback when they produced an infra-red stethoscope listener with earcups. I said to them: "I can't use these in my ears, do you have a neck loop that works with the infra-red system?" The answer was: "Sorry this is all we have". So I went into the cinema and took my seat; put my CI onto 'T'. with the stethoscope listener tight around my neck (not in my ears, as I think intended), and HEY PRESTO – even with no subtitles I could hear every word – so the stethoscope arms were creating the magnetic loop required by h/aids or CIs with 'T' switches on, with no problem.

So, ladies and gentlemen, if you feel like an enjoyable evening out – the film is good and may be able hear! While on the subject of the Cornerhouse, I think it only fair to say that before I had my CI, the Cornerhouse was the ONLY cinema I could visit AND understand the film, despite NEVER having been able to use/wear a h/aid, and that is because they show a lot of high quality foreign films ALWAYS with sub-titles.

I believe if you become a member, it entitles you to a discount.

However, I think I'm correct in saying that under the terms of the 'Equality Act' of last October, all cinemas and theatres are required by Law to provide equal access to their films etc which must mean providing loop or infra-red systems for access to the spoken word.

Happy film-going!
Bill Allen

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“JOIN CICADA Club”

“Set up by the hospital for you”

Created in 1993 by Professor Ramsden to provide post operative information and support for patients and their families.

*“Get support and help from others with
Cochlear Implants”*

Learn from other people’s experiences and issues. We aim to help each other socialise with a friendly group.

We organise exclusive events throughout the year for club members, friends and families which includes barbecues, discounted visits to Activity centres, tours of famous landmarks and bowls competitions and Christmas meals.

*“Get exclusive access to hearing support
professionals”*

We have meetings twice a year for members where hearing support professionals talk about new developments, changes in benefits and support services. Club meetings are provided with palantype services.

“ReSound Magazine”

Have your say, see your letter or articles in our twice yearly colour magazine with news and information about all the clubs activities.

*“Free membership for the first year for patients
and their families and a small
subscription subsequently”*

Just fill in the form provided by the clinic or go to the website www.manchestercicada.org.uk and fill in the online form or contact the club secretary.

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