

NEWSLETTER

MAGNETISE

www.hccig.org.uk



Report from the Chair

Welcome to the winter edition of our newsletter. We've just had our Carol Signing in Hertford and the countdown to Christmas has begun so on behalf of the Trustees Darren, David and I we wish all our members, representatives from Cochlear, Medel and Advanced Bionics and the staff in the Cochlear Implant Department at the RNTNE Hospital joyful celebrations and a Happy New Year!

We'll see some of you over the weekend in Eastbourne and more at the Christmas meal in Holborn so look forward to socialising, something all of us have found difficult without our implants. Just to say though don't forget to keep an eye out for anyone who is struggling with conversation at meals as they can be noisy affairs and make sure they are included because even having an implant doesn't always make such situations easy!

Thanks go to all who have returned their membership forms and subscriptions and this is a gentle reminder to those who haven't done so yet to get them in by 31 December or you will miss out on our events next year and the latest CI news as we have to remove your details from our database to comply with Data Protection rules.

Next year's programme of events is being pulled together and we hope many of you will join us at some or all of them. Just pencil in the dates shown in the next column and we'll send more details in due course. If you have any ideas or are willing to organise something then do get in touch as we've said before it's your group and we're keen to hear what you want to see happen. Even feedback on Magnetise is welcome as we try to make sure we put in articles that will be useful and keep you aware of research and developments that are happening that may help with your next upgrade!

Newsletter updates If you would like to submit an article for the next publication of Magnetise then send it to hccigs@gmail.com by **28 February**. Your newsletter will be emailed to you unless you ask for a hard copy to be posted.

Dates for your Diary

WINE BAR

Tuesday 9th February 2016

6-9pm

Lounge 33 Wine Bar,

33-35 Brooke Street, Holborn,
London EC1N 7RS.

Same venue as before but change of management and name. Nearest tube Chancery Lane exit 2. Just come along, join in and catch up on the latest CI chat.

**HCCIG AGM Advance Notice
Saturday 23 April 2016 12noon**

Keep this date free in your diaries as we plan our next AGM and lunch in Enfield. Programme to follow.

**The London Canal Museum
and Tunnel Trip**

Sunday 15 May 2016

www.canalmuseum.org.uk

Details will be sent out so you can reserve your place when we have confirmation our group booking has been successful and a lunch venue has been organised.



Bending the Spend: Expanding access to hearing technology to improve health, wellbeing and save public money



Claire Johnson was invited to stand in for Jenny at this conference where the Report on 'Bending the Spend' was launched Tuesday 13 October to professionals in the Hearing Impairment arena, MP's and representatives of various organisations such as ours.



This was the third conference The Ear Foundation had held at Westminster Central Hall. The previous report they produced highlighted the cost of NOT providing cochlear implants and hearing aids for those that need them, and the latest report: *Bending the Spend*' takes the arguments further. They demonstrate how the introduction of hearing technologies during the 1990's and into this century, has significantly reduced the costs of managing hearing loss- and how hearing technology more than pays for itself when these cost savings are taken into account. With our ageing population and increasing need to be able to continue working and communicating, the need for improving hearing services has never been greater.

The conference highlighted the effects of the current financial challenges to the NHS on audiology services, not only in England, but elsewhere, and some of the innovative ways in which changes in service delivery can save additional funds, and make services more effective.

The Ear Foundation was arguing for more innovative service delivery models to cut down the time taken to effect repairs of CIs and hearing aids for example. It wanted to press for improved education and training for professionals and welcomed the publication of the Action Plan by NHS England as a strategic model to be applied elsewhere.

Lilian Greenwood MP and Patron of the Ear Foundation is shown in the photo with the Chair Brian Lamb and Sue Archbold, Chief Executive at the launch of the report in the House of Commons. To achieve the aims outlined in this report and the earlier one the Ear Foundation is leading the Adult Cochlear Implant Action Group that has been set up to promote greater access to cochlear implants and more awareness among the medical and audiological professions of their benefits. The group includes all the key professional and user associations. If you want more details

about the campaign contact Sue Archbold or Brian Lamb c/o Marjorie Sherman House, 83 Sherwin Road, Nottingham NG7 2FB. Telephone: 0115 942 1985.

“Decent hearing (as is decent vision and health) is a benefit that should be universally available to all for nothing.” Cochlear implant user.

Personalised long-term follow-up of cochlear implant patients using remote care.

This was one talk given at the Ear Foundation’s conference by **Helen Cullingham**.

Many resources are required to provide post-operative care to CI patients. The implant service commits to a lifetime follow-up, which may be up to 100 years for a baby! These services are provided by specialist centres which may be several hours away from the patient’s home necessitating travelling expense, time off work and family disruption. Currently UK implant centres review patients on a clinician-led schedule; this means that review appointments can occur that provide little benefit to the patient. Making this care pathway patient-centred instead will provide a more efficient service and allow more timely identification of issues.

Helen is working on a project to design, implement and evaluate a person-centred long-term follow-up pathway for CI users offering a triple approach of remote and self-monitoring, self-adjustment of devices and a personalised online or Smartphone intervention package for testing their own hearing at home, information and self-rehabilitation.

Potential benefits for the patient are:

- More stable hearing (problems identified and resolved quicker)
- Convenience of not travelling to routine appointments
- Reduction of travel cost and time and disruption to family life
- Increased confidence to manage own hearing

It may mean that the clinic/centre resources are freed up (time, money and space) to see complex cases and the expanding population of new patients.

Helen is working as a clinician and researcher at the University of Southampton Auditory Implant Service. She has asked if HCCIG members would help in the project so if you have received the email from Jenny please think about taking part as this is a sure way of *‘Bending the spend’* and gives CI users control of their processors and who knows you may be mapping the future!

What about people?

Dr Lorraine Gailey Chief Executive, Hearing Link

The cost of adult acquired hearing loss is well established. Without appropriate management, deafened adults are at high risk of mental ill health as a result of the communication difficulties they encounter within their families and their social life. Furthermore, the incidence of mental ill health in close family members is also increased and the risk of family breakdown is significant. Then the added cost to the country’s economy of lost productivity due to unmanaged hearing loss is also significant.

Lorraine summed up the conference with the following observations:

- Information needs of patients are being neglected as Hearing Link get calls all the time saying people don't know where to go or what to do when they face hearing loss
- What does the current NHS system do? It sends them to the GP who cannot be all things to all people! The service cannot be delivered in the same way it's always been done. Need a new approach to allow people to take responsibility for themselves and to provide them with the information and tools to do that
- The fact that North Staffordshire Health Authority had announced it was withdrawing provision of hearing aids to those who have mild to moderate hearing loss is not the answer to cutting costs as it is ignoring scientific evidence that if do provide hearing support then long-term costs on NHS will be less
- There is capacity of professionals to be negligent as audiologists do not refer people to Cochlear Implants being a solution to be explored when hearing aids inadequate
- Choices are being limited because of a lack of the right information both for professionals and for people suffering hearing loss and their families who want to help them – it is well known that it takes about 10 years before someone takes action on their hearing loss because of the stigma and general ageing process

She ended the conference with the comments, *“Less of the same won't do! We don't want bells and whistles but we do want the bells to stop!”*

Jewellery Sale



David Gordon and Claire Johnson attended Hertford County Offices on 12 October and with help from Tesco's Community Champions Lynn and Louise plus Melanie we raised £330 from sale of jewellery items for HCCIG. Well, as they say, *‘Every little helps!’*

Hearing Matters
report launched



The week we launched [our landmark Hearing Matters report](#), which reveals that there are now 11 million people in the UK with hearing loss. In just 20 years, it'll be one in five of us.

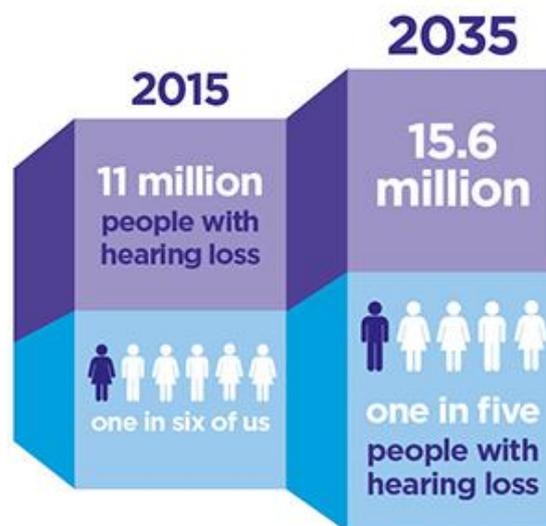
Hearing Matters sets out clearly what we want government, regulators, public services and companies to do, to tackle the growing prevalence and devastating impact of deafness, tinnitus and hearing loss.

Our practical recommendations include **stopping the cuts to NHS hearing aids, investing in treatments and cures, and offering better support at work.**

What's the biggest hearing loss issue you want addressed? [Tell us your no. 1 concern today](#), and we'll feed this into our campaigning work. Go to <http://www.actiononhearingloss.org.uk/get-involved.aspx> and join our campaigners in lobbying for change.

For those who are already involved in supporting campaigns thank you for your ongoing and invaluable support. We promise to make sure your voice is heard.

Dr Roger Wicks
Director of Policy and Campaigns



HCCIG Carol Signing

Saturday 28 November at Hertford Farmer's Market from 11:00-14:00hrs.

We were invited to provide some Christmas spirit by signing carols in three different areas of the Market. A good contingent of 20 members turned up with at least 14 involved in signing the songs – the practise sessions on 3 Saturdays paid off as we raised £216 for the group to continue its work increasing awareness of cochlear implants and keeping members up to date on developments in technology and access to make a difference to recipients and their families. Mary Dent our Signer kept us in sync, hands and lips but can't say the same for our line dancing!

At the end we repaired our voices and lifted a glass to the King in a local hostelry!



StageTEXT

Every word counts

'Tis the season for pantomimes and shows so make the most of seeing old favourites or seeing a new performance that is captioned. Go to <http://www.stagetext.org/> to find out where this service will be available whether you are at home for Christmas and New Year or away. Just three in the Home Counties area give a taste of what will be on:

The Twelve Days of Christmas



Mon 7 Dec 2015, 12:00pm

Sat 12 Dec 2015, 3:00pm

Fri 18 Dec 2015, 7:00pm

Chickenshed

Chase Side
Southgate
London
N14 4PE

Phone: 020 8292 9222

Email: accessbookings@chickenshed.org.uk

Robin Hood



Sat 19 Dec 2015, 7:00pm

Theatre Royal Stratford East

Gerry Raffles Square
Stratford East
London
E15 1BN

Phone: 020 8534 0310

Email: tickets@stratfordeast.com

Snow White



Sun 3 Jan 2016, 12:00pm

Marlowe Theatre

The Friars
Canterbury
CT1 2AS

Phone: 01227 787 787

Email: sarah.munday@marlowetheatre.com

Disclaimer – HCCIG A voluntary group funded by members

HCCIG accept no responsibility for any information relating to third party organisations featured in this newsletter. While HCCIG makes every effort to ensure details are accurate, we advise our members to check these with the organisations concerned. HCCIG does not endorse any product or service of, nor does it verify any preferential treatment, offered by the organisations. All queries should be directed to them. Certain of the offers and services featured in this newsletter are only available to customers of those organisations. HCCIG does not provide medical advice or make recommendations with regard to any particular implant and no article in this newsletter should be construed as doing so.

Contacting HCCIG

Please use email as the main way to contact Jenny as she is often out and about on HCCIG business or busy with family commitments. That way you can be sure your messages will be picked up and a reply returned in due course. Thank you.

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Hospital, Cochlear Implant Department,
Gray's Inn Road, London WC1X 8DA

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Fax: 020 3456 5003

Text: 07899 748 917 (Strictly text only)

Email: cirepairs@uclh.nhs.uk

Email: cioffice@uclh.nhs.uk

Adult programme

Telephone: 020 3456 5001

Email: Jeanette.Sanders@uclh.nhs.uk

Paediatric Programme

Telephone: 020 3456 5002

Email: Lorna.White@uclh.nhs.uk

Batteries are sent out by 2nd class post.

Social Media Update

Website – www.hccig.org.uk

If there is anything that you feel should be displayed on our website get in touch.

Blog - Guest blogger contributions welcome, email hccig@ymail.com

Facebook –to find us search for Home Counties Cochlear Implant Group and feel free to add comments, photos or updates on any member news.

Twitter – please keep tweeting away at HCCIG and do follow us.