## Newsletter

NATIONAL COCHLEAR IMPLANT USERS ASSOCIATION NEWSLETTER



## The Forgotten Many: Potential demand for Cochlear Implants from Adults By Chris Raine

It would be fair to say that Cochlear Implantation is a well-established treatment for severe to profound sensori-neural hearing loss. In the NICE report of 2009 it mentions that there are some 615,000 adults in the United Kingdom with a profound hearing loss. Yet from recent annual returns from CI centres indicate we are supporting just over 6000 adults and just less than 5000 children. The incidence of implantation in adults in this country is notably lower compared to that of our major European partners. It is important to not only to plan clinical need but also to bring in the commissioning of services

#### What is happening in the UK?

To try and address this we have looked at surgical data and compared it to the anticipated incidence of adults with a severe to profound hearing loss. Surgical registration data was kindly supplied by the three major manufactures from 2006 – 11. The potential incidence of hearing loss for various age groups was based on studies performed by Adrian

Davis. The incidence based at 90 dB at 1kHz was applied to the population statistics of 2011.

The table highlights the fact that annual incidence increases significantly over the age of 60. Whilst the rate of surgery is relatively high in the younger age groups we appear to be failing the older age groups. Overall, surgical rate is about 5% for adults. There may be a slight over estimate in the annual incidence as 1kHz was used and selection criteria used by NICE is 90 dB at 2 and 4 kHz.

The reported new adult patients implanted via returns to British Cochlear Implant Group (BCIG) in 2011-12 were 508. Some of the differences in the table are related to operations in the over 80's and where the date of birth was not recorded. Even so the impact is still low.

At the recent BCIG annual meeting in Kilmarnock we heard about the increased issues of dementia related to both loss of vision and hearing. It would be interesting to know if hearing aid users and

those implanted benefit?

How do we reach out to adults and especially the older population? BCIG has initiated an awareness campaign.

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Age Group	Population	Annual Incidence	Surgery	%
18 - 29	9902000	99	37	37
30 - 39	8078000	428	69	16
40 - 49	9006000	540	69	13
50 - 59	7493000	734	79	11
60 - 69	6648000	4487	81	2
70 - 79	4356000	3049	82	3

15th June 2013 - Summer Meeting and AGM will be held at Queen Mary, University of London, Mile End Road, London E1 4NS

**DIARY DATES** 

9th November 2013 - 'Technology Day' at Hearing Implant Centre, St Thomas' Hospital, London, SE1 7EH (details enclosed).



The main method is to have posters (see illustration) displayed in ENT and Audiology departments. We are also trying to get them into primary care centres and in public areas such as libraries. Also from surveys run we have identified the need to keep on educating fellow colleagues and audiologists to identify those who are struggling with their hearing aids. However there may be literally thousands who might have tried hearing aids, given up and are now 'lost to follow up'. Clearly there is a lot more work to be done to understand the complexities of how we cope with deafness as we get older.

### **MANUFACTURERS NEWS**

Cochlear™ is pleased to announce that Chemistry student Georgina Grimshaw has been awarded the £6,000 Graeme Clark Scholarship Award, which will help to support her through university. At a ceremony in Manchester, the Lord Mayor Councillor Elaine Boyes, accompanied by the Lady Mayoress Linda Geoghegan presented Georgina with her cheque.

Born profoundly deaf, Georgina 20, was fitted with a Cochlear™ Nucleus® implant at the age of four, which she says changed her life. Georgina attended mainstream school and with the support of friends, family and hearing healthcare professionals at the Manchester Auditory Implant Centre - as well as lots of hard work and determination - Georgina gained excellent A levels and top marks in an extended project on the development of technology for deaf people.

A second implant at the age of 18 helped Georgina to understand the direction of sound more and to hear better when amongst groups of people. She now manages well amongst peers at Manchester University on her chemistry course with some support from a note-taker in lectures. She enjoys swimming, water polo, fencing, is a qualified lifeguard with the Royal Life Saving Society and volunteers at a local disabled swimming club.

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As Georgina says, "The advances of cochlear technology in my lifetime have been truly life changing for me and have allowed me to achieve my personal goals like anyone else. With the help of this scholarship, I'm now a step closer to reaching my ultimate goal which is to be a successful scientist.

Being deaf won't stop me if I work hard and have a bit of luck along the way."

Brian Walshe, Marketing
Manager of Cochlear says, "The
annual UK Cochlear Graeme
Clark Scholarship was set up to
help implant recipients achieve
more in further education and
we are delighted that Georgina
has won. She certainly deserves
our support as she pursues her
dreams of becoming a scientist.
Who knows, she may even
play a role in our research and
development one day!"

A supportive team of hearing healthcare professionals from the Manchester Auditory Implant



Brian Walshe and Georgina with the Mayor, Elaine Boyes, and Mayoress, Linda Geoghegan, of Manchester

Centre attended the ceremony. As Lise Henderson, Paediatric Co-ordinator says, "Georgina's cochlear implant has given her the opportunity to achieve so much both personally and academically. She tried so hard with her hearing aids but they just didn't give her the access to speech that she needed and the implant made listening and learning so much easier for her. The whole family have worked so hard for many years to get the most from Georgina's implant and they should all be very proud of what she has achieved."

To find out more about the Greame Clark Scholarship Award, please contact Kate King: kking@cochlear.com or 07793 652182.

#### NEW SOUND PROCESSOR COMING FROM ADVANCED BIONICS

Advanced Bionics (AB) has announced that their next generation behind-the-ear sound processor is awaiting regulatory approval.

Under the Sonova Group, Advanced Bionics collaborates with Phonak, bringing together the most advanced cochlear implant and hearing instrument innovations into one family. Designed for improved hearing in a wide variety of listening settings, the all-new processor will featurestate-of-the-art technologies and accessories available exclusively from Advanced Bionics and Phonak for the first time in the market's history. The new processor will be sized 40% smaller than AB's current behind-the-ear processor, provide unprecedented performance capabilities and offer industry-leading wireless connectivity options.

"We realise there is huge anticipation for AB to introduce the next-generation processor. Choosing AB now gives recipients in the UK the option to enjoy the most advanced technology when it's introduced," said Hansjuerg Emch,

Group Vice
President of the
Sonova Medical
Division within
which AB resides.
"AB is known for
industry firsts.
With technology
from AB and
Phonak combined,



the next processor to come from us will be history making for the market."

## Innovative New Sound Processing Designed for Improved Battery Life is Approved by the TÜV

AB are also pleased to announce TÜV approval for the global distribution of HiRes Optima™\* sound processing. The world's newest sound strategy for cochlear implant recipients, HiRes Optima delivers optimized battery life with the same great performance as AB's patented HiRes Fidelity 120™\* processing. AB cochlear implant recipients using this new technology enjoy an average improvement of 55% in battery life, giving them considerably more time to hear their world before needing to change a battery.

#### Advanced Bionics launch new HiFocus Mid-Scala electrode

The all-new HiFocus Mid-Scala electrode designed to help preserve residual hearing is now in use in the UK!

AB announces the launch of the HiFocus™ Mid-Scala electrode. The latest offering in AB's HiFocus™ electrode family, the HiFocus Mid-Scala is designed to help protect the delicate structures of the cochlea for the preservation of residual hearing without compromising performance. The new HiFocus Mid-Scala array is the latest innovation in electrode design. Developed through extensive research and state-of-the-art manufacturing processes, the HiFocus Mid-Scala electrode has been designed for optimal mid-scala placement in the cochlea to protect its delicate structures and preserve residual hearing. It is fully upgradeable for next-generation sound processing and provides recipients with the opportunity to enjoy the best possible hearing now and improved

hearing in the future as new technology is introduced.

"For anyone with significant hearing loss, the preservation of any hearing that remains is important when getting a cochlear implant," said Hansjuerg Emch, Group Vice President of the Sonova Medical Division within which AB resides. "At the same time, we need to ensure that the electrode position in the cochlear enables the best possible electrical stimulation of the hearing nerve. We developed the HiFocus Mid-Scala electrode to do just that."

Featuring the industry's smallest pre-curved array, the HiFocus Mid-Scala is the only pre-curved electrode developed for the latest soft surgery approaches, including round window insertion, to suit surgeon preferences and individual recipient needs.

#### **MED-EL Music Grants 2013**

MED-EL music projects have been bringing joy to cochlear implant users young and old since the premiere of "Noise Carriers" in 2008, so it is with great pleasure that MED-EL UK announces the launch of the MED-EL Music Grants 2013. These special grants will provide the opportunity for two lucky MED-EL implant users to learn or improve their playing of a musical instrument of their choice. There are two categories of Music Grants: one for applicants under 19 years old and one for 19s and over. To be eligible you must be the recipient of a MED-EL hearing implant. Applicants under the age of 18 years old must have the consent of their parent or legal guardian.

The winners of the grants will receive a musical instrument of their choice up to the value of £500 and MED-EL will pay for one 30 minute lesson per week for one year. There is also a £30 allowance for sheet music. Travel expenses will not be covered. All tuition fees will be paid directly to the music tutor.

Applications are welcome from all MED-EL implant users with an interest in music, whether they are complete beginners or have prior musical experience.

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Learning a musical instrument requires commitment, so the winners will be selected based on their enthusiasm and motivation.

All applicants under the age of 18 years must have parental consent and the deadline for applications is 29th July 2013. Please email conferences@medel.co.uk for an application form and terms and conditions or call the marketing team on 01226 242874.

Cassandra Brown, MD of MED-EL UK states: "Music is life-enhancing and something most of us take for granted. MED-EL is committed to providing our users with the best possible listening experiences, including music appreciation. The opportunity not only to listen to music, but to make music will bring the winners of these awards pleasure for years to come."

# Cochlear Implantation for single-sided deafness and incapacitating Tinnitus: Eight years experience with this new indication that changes lives

The Graham Fraser Memorial Lecture by Professor Paul Van de Heyning (University of Antwerp, Belgium)

Single sided deafness means that there is no binaural hearing and the people affected have considerable difficulties with conversation, understanding speech in noise and the localisation of sound but 42% also suffer severe tinnitus in the affected ear.

The team at the University of Antwerp spent eight years researching the problem. Of fifty nine patients with single sided deafness and severe tinnitus twenty nine were fitted with a MED-EL cochlear implant and a further thirty with bone conduction devices. Most patients fitted with cochlear implants for the most part got considerable relief from their tinnitus; 25% had complete suppression of tinnitus, for 43% it was attenuated while 30% found their tinnitus was unaltered. Of the thirty patients fitted with bone conduction devices; for 83% there was no change, 7% found their tinnitus was worse, 3% gained total relief and a further 7% some relief from their tinnitus.

The conclusion was that for people with single sided deafness and incapacitating tinnitus cochlear implantation in the affected ear improves their hearing capabilities and can significantly decrease their tinnitus, loneliness and distress, or in other words there is a new indication for cochlear implantation.



Professor Paul Van de Heyning with Pat Fraser

#### **EURO-CIU MEETING IN ISTANBUL 6th -7th April 2013**

The Annual Assembly was preceded by a conference about cochlear implants and children. We were given a very interesting insight into the great efforts made in Turkey to reach out to all profoundly deaf children by several speakers. It is impossible to do justice to the organisers of, and speakers in, what was a most thought provoking day but the next few paragraphs will, hopefully, provide some idea of the proceedings.

Turkey has a population of 75.6 million. Of the 9,000 cochlear implant users in the country 79% are children – auditory testing is compulsory for all new born babies and programmes for screening children at the pre-school and school age are being put in place. For financial reasons bi-lateral implants are rare. The costs of implantation are met by Social Security but other ministries are responsible for funding other services such as special education and the purchase of equipment but the co-ordination of the various services is problematic.

After implantation multi-disciplinary teams work on the rehabilitation or habilitation of the users. Quite a high proportion of the children have other handicaps in addition to deafness. Special schools are

available to those who need this provision but the aim is for most children to go on to mainstream education when the time is right and they are able to express themselves verbally, have intelligible speech and the social competence and academic skills needed to integrate successfully. Mention was made of the problems in providing programmes for training the specialists in audiology and other disciplines to deliver all the services, shortage of equipment such as FM systems and quite severe short comings in the provision of special education.



Speakers from other countries covered topics such as the need for parent counselling and the techniques used by audiologists and therapists with children to improve their listening and communication skills. Great emphasis was laid on the role played by parents in bringing up their deaf children and their need for support and help. The use of play in helping children to develop their language and social skills was ably demonstrated. The value of children in mainstream education being able to meet other children with cochlear implants and join in activities with them on a regular basis at special schools or a holiday camps was also recognised.

#### The Annual Assembly

This was the best attended Assembly I have ever been to with members from large and small European countries packed into a room that could have been a little larger but the atmosphere was excellent and very friendly in spite of language problems. Tricia Kemp and I represented the UK. Slovakia and Serbia were represented for the first time and the Bosnia Herzegovina candidature is being considered. English was the main language and our Palantype operators provided an excellent transcript that was projected onto screens all around the room.

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The annual enquiry which is now being undertaken by the Ear Foundation was considered of great importance for providing information on cochlear implantation in the member countries. Great strides, as reported in the last newsletter, are being made in making our presence felt in relation to the European Commission by participation in the European Platform for deaf people.

The next meeting of the assembly will take place in Hungary and the symposium in the following year in Antwerp.

Alison Heath

# The Benefits of Having Two Cochlear Implants: a research study by University College London and Cardiff University

Bi-lateral CI users are needed to help with this important study. There will be up to 40 participants who will be required to visit the Department of Speech, Hearing and Phonetic Sciences, UCL (near Euston Station) for various tests. The total duration of the experiment will be up to 2 hours. Expenses will be paid. If you are interested please contact: Professor John Culling, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CFR10 3AT Email: CullingJ@cf.ac.uk

#### Need advice about hearing loss? We can help

James says.....' As soon as I contacted Hearing Link's Helpdesk I felt I was talking to people who really understood my problems. Doors suddenly opened: a Community Volunteer came to visit me and my family at home, and we spent 5 days with other families on a Rehibilitation Programme, which was brilliant!

I have now called on the Helpdesk at every turn – lipreading classes, equipment, benefits, and I am now subscribing to their excellent feature magazine, Hearing Link Matters. Foe me the Helpdesk has been a lifeline, I know it's always there when I need it.'



'The person on the helpdesk was friendly and knowledgeable. I knew I'd come to the right place.'

Hearing Link works to support people with all degrees of hearing loss, including those with an acquired profound hearing loss and implant users.

Whatever your query we will provide a friendly and personalised response. Contact our Helpdesk today!

Hearing Link, 27-28 The Waterfront, Eastbourne BN23 5UZ Telephone (voice) 0300 111 1113

SMS 07526123255

Fax 01323 471260

enquiries@hearinglink.org

Hearing **%**Link

#### Phonak FM Systems

# Still Struggling to Hear in Background Noise?

At Phonak we understand that whilst hearing aids allow people to hear better, there are still some everyday environments that can present challenges:

- Listening to Television
- Using the Telephone
- Travelling in the Car
- Noisy Environments

Phonak FM systems have been designed with these situations in mind and could greatly improve your hearing experience. For more information, please visit www.phonak.co.uk.





www.hearinglink.org







## Would you like a demonstration of Phonak FM systems?

If so, the Ear Foundation now offers a dedicated service providing the opportunity to try, purchase and set up FM systems on site at their Nottingham centre. For further information please contact Claire on 0115 942 1985 or via email at claire@earfoundation.org.uk



PHONAK life is on

#### **Message from the Editor**

We hope you will find food for thought in this issue of the newsletter. What concerns me most is that only a few adults with severe or profound hearing loss in this country actually have a cochlear implant though they are entitled to them. It seems that the message that CIs could help them is not getting though. Perhaps the audiologists are failing to tell those who struggle with hearing aids that a CI might help them? Those who no longer go to hearing aid clinics are virtually 'lost' if they do not seek help from their GP. How do we reach out to them? Most publicity around CIs is concerned with children and deafened adults rarely feature in this. Any ideas as to how we can help the British Cochlear Implant Group with their campaign (see first article) would be very welcome.

The next issue of the newsletter will be in the autumn. Material for this should be with me by mid September.

Alison Heath

#### **Problems with TV SubTitles**

We all love subtitles even we wish we did not have to rely on them . Typically we experience three types of problem. First the time delay between the spoken words and their appearance as subtitles. This is absolutely unavoidable as the subtitler takes a finite time to digest the spoken words and then 'translate' them into subtitles. The operator speaks into voice recognition computer (VRS) software but still with a delay. We get used to this and it's acceptable provided the time delay is constant. But then the next problem arises. A mistake or mis-interpretation produces a garbled result and the operator tries to correct it, interrupts the flow and the correction appears later. Despite all the appeals for this not to happen VRS has still along way to go to being able to produce 'perfect' translation. Many viewers actually prefer that the corrections are not made and that the flow of subtitles is maintained. We can interpret the true word or meaning from the context of the programme.

And the last problem is when there is a complete break in the flow and gaps appear often with multiple messages. This is caused by operators trying to manage different forms of input mixed in with corrections.

A new live subtitling platform is promised this summer by Red Bee Media who supply BBC's subtitled output and it is hoped this will resolve many of the problems above.

Richard Byrnes

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#### Disclaimer

Whilst the Association uses it's best endeavours to provide accurate information on the subject of cochlear implants it does not provide medical advice or make recommendations with regard to any particular implant or equipment and no article in this newsletter should be construed as doing so.

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