



David Cotter – A Users Personal Experience of Bilateral Cochlear Implants

At last year's NCIUA conference at Queen Mary's College London David Cotter gave a short talk on his experiences of having had a Neurelec Binaural cochlear implant fitted – this is a summary of his presentation

Hello I am David Cotter and I had a Neurelec Binaural cochlear implant fitted at Southampton General Hospital on 17th January 2012. The history of my hearing loss was that it was first discovered around the age of 10. At this point it was not significant and I was able to complete school, college and university whilst not generally wearing a hearing aid. After university I lost the ability to be able to use a telephone and the period of my 20's and 30's was one of continued deterioration until basically I was profoundly deaf and the use of a hearing aid was a total necessity. I visited the Jean Causse clinic in France and they suggested I had cochlear otosclerosis and prescribed sodium fluoride to stabilise the situation. This appeared to be the case but by now I was profoundly deaf. My visits to the Royal Surrey Hospital Guildford became routine annual events where there were no potential improvements except possible changes in the type of aid I wore. Cochlear Implants were briefly discussed but appeared to relate to people who had more hearing loss than me so I never really gave them much consideration.

However in March 2011 Dr Jayarajan told me the criteria for acceptance for cochlear implants had changed and that he would refer me for one if I so wished. As I had already almost dismissed this option I decided to go away and consider this and get back to him. This coincided with a reorganisation at work which meant for the next month or two I was involved in a process of possible redundancy. The night I knew I had a position going forward I went out and met a cochlear user in Egham – she told me how happy



Nigel Williams and David at the Summer Meeting

she was with the process and I then decided I would go ahead and see if I would be eligible.

There then followed a period of four months of assessments and tests and I must say that the staff at the Southampton Auditory Implant centre are marvellous. During this time my attitude to the implant process changed so much as I now realised this would be my real chance to improve my hearing.

My initial choice of implant was to be a mono AB unit. My logic was this would be less risky than a binaural operation, less equipment to wear and the fact that I would have my 'bad' ear implanted and then I would still have my good ear with the aid to fall back on. When we came to the choices part of the process Southampton told me that they preferred not to implant the 'bad' ear – which in

DIARY DATES

14 June 2014 - Summer Meeting and AGM will be held at the Clore Management Centre, 25-27 Torrington Street, London WC1E 7JL

my case was the right ear which I had not worn a hearing aid on – but wanted to implant the side that had been stimulated. This knocked me back as my plan was now unlikely to be allowed or recommended. But I did say please go ahead with AB. The next day after much soul searching I decided I should go for the Neurelec binaural option and have both sides benefiting from the implant – this was because if I implanted my ‘good’ ear then my plan to have a fall back to the aid on the good ear disappeared and it seemed logical then to go for the system that would benefit both sides of my hearing.

The operation was then delayed as they needed to find a double slot – the operation takes over nine hours for the Neurelec binaural unit. This all went ahead and fortunately I did not experience any significant negative effects afterwards. Six weeks or so after this I had the implant switched on at Southampton by Dr Helen Cullington.

This is an amazing and truly personal experience. No amount of discussion in advance really prepares you for this. Within an hour or so of switch on I was beginning to be aware of the potential benefits this would have. I was able to hear the shape of words – I could not make them out but I could differentiate between them – and what this meant fundamentally was that for the first time in 25 years or so I was actually listening to speech rather than trying to see speech. Each day from then on I would be discovering new sounds and it seemed a process whereby I would ‘normalise’ a sound and from then on I would hear it that way. For example a squeaky chair would start to sound like some weird electronic organ then I would hear it as a squeak. After that it would always be a squeak.

Even in the early stages I was very conscious of what I would describe as sound having balance. I was not hearing left or right I was hearing as if the sound came in directly in the middle of my head. There was no imbalance on left or right. From a result based perspective before the implant wearing my aid I had a Bamford Kowal factor with no lip-reading of zero. At three months after switch on this was over 40% and at the one year test this was 74%.

As the purpose of this presentation is to describe my experience of binaural implants I will explain issue specific to that element.

The unit I wear is comfortable and the additional smaller processor is anchored to the main unit.

This does not pose any real problems and am able to lead an active life such playing golf and cycling with no need to take the unit off.

Sound perception seems very central and one thing we focus on in mapping sessions at Southampton is maintaining that balance so that one side does not dominate. It is difficult to describe but there appears to be a synergy in wearing the binaural unit like $2+2=5$. Individually the processors deliver improvements but only when both switched on do I get an almost mushrooming effect in my perception.

I took part in a PHd study test at Southampton and they found that the binaural unit I was improving my spatial awareness of sound and that background noise was less of a problem for speech recognition when using the binaural aspect. These will be tested again this year to monitor any change.

I can now listen to music again. It appears to me that I also hear this sound centrally rather than on one ear or the other. Southampton actually used a mapping so that I can plug directly into an iPod that is connected to the main processor only but I hear the sounds on both sides. I have been able to see The Rolling Stones twice since I was implanted and this was for me a pure joy.

I now use the telephone regularly with a good degree of success. I have two main methods for this – a phone with a telecoil and an iPod adaptor for the blackberry mobile. Given the iPod setting they did at Southampton when connected on the mobile phone I get sound perception on both sides and this improved my telephone comprehension significantly. I should point out this was after a period of ‘telephone training’ and this did take time and was hard work indeed. I used to have tinnitus issues – since the implant this problem has all but gone.

I have help to test a wi fi version of the Neurelec binaural unit. This is still in development but may in future offer more options to the user.

To conclude, as this is my only experience of having a cochlear implant I can only describe what happened to me and make no judgements as to whether this choice might be beneficial to others or offer some advantages over and above what is available in a mono system. Most people I have met seem happy with their implants.

For more information about Neurelec see their website: www.neurelec.com

Adult Deafness

Time for a new approach?

This conference arranged by the Ear Foundation took place on 15th October 2013 at Central Hall Westminster and had a packed programme that included several speakers ranging from MP's and Professionals to cochlear implant users who talked passionately about their experiences.

The aim of the day was to focus on adult deafness and its impact which was linked to isolation, depression, dementia and a greater chance of unemployment. It was noted by one speaker that around 45% of people who go to their GP about their hearing loss are not referred for audiological assessment. While recognising the huge changes in hearing technologies to-day it was acknowledged that access to these technologies is still difficult and information is often not up to date. The conference suggested that it is time to take a new look at adult hearing loss and the gap between the potential of today's technologies and the reality of provision.

The morning session was opened by Sue Archbold and looked at current services and included speakers from both the private and public sectors. The first speaker was Stuart McNaughton who talked about his personal experience of living with hearing loss and gave a first hand account of the impact receiving bilateral cochlear implants has had on his life. Adrian Davies gave a Strategic overview of Health and the Healthcare System in England while Barry Downes gave an independent sector perspective on The Future of Adult Hearing Care. Ruth Thomsen talked about her role as an audiologist demonstrating how service providers work collaboratively with patients, staff, social services and the third sector to ensure a 'joined up service', takes care closer to home and is fit for the future. Mark Lutman and Stephen Lloyd MP spoke passionately about the need for adult hearing screening services and their cost effectiveness. They argued that screening is more cost-effective than relying on GP-referral and would result in improved quality of life for many older adults. Kevin Munro talked about the importance of communication and the impact acquired hearing loss can have on the quality of life. The morning concluded with a look at the latest research on the impact of hearing loss in relation to dementia.

The afternoon session was opened by Brian Lamb and focused on cochlear implants in particular and the enormous benefits these can offer adults.

Speakers looked at the current guidelines and at outcomes from cochlear implants from the perspective of the user. Adam Beckman spoke about current practices and the framework currently adopted by audiologists. He argued that a different model of care might benefit adults with hearing loss and ensure that they can get the most out of their life. David McAlpine explained why the earlier an implant is received the potentially better the outcome. He looked at some of the reasons why adult implantation is lagging behind that of children in the UK especially with regard to bilateral implants. Chris Raine talked about Adults and Access to Cochlear Implants and questioned why compared to other European countries our use of cochlear implants is relatively low suggesting that there were various reasons for this ranging from stringent criteria to patient and professional awareness. Dr Andrew Dunlop gave a professional and personal experience as a GP who experienced sudden hearing loss. He spoke about the successful cochlear implant he received within a year of his hearing loss and how he was now able to practice as a GP again but recognised that many adults in his position are not as fortunate.

He suggested that there is 'an iceberg of unmet need within the community at large' and concluded by saying that the cochlear implant is a truly wonderful piece of technology and that we should ensure that it is put to appropriate use as widely as possible. Sheetal Athalye talked about research she had undertaken relating to experiences of adults assessed for Cochlear Implants which did not proceed and explained how this research had resulted in a number of suggestions regarding the actual assessment process. This was followed by Darren Savage who talked about his personal experience of assessment for a cochlear implant and how after having been originally turned down due to not meeting the criteria he had now been re-referred for assessment and was hoping for success the second time around. Lorraine Gailey talked about the need for good communication. She suggested that despite the rapid advances in technologies it is never just about technology. We need to consider the individual and recognise that however complex the technology is human beings are often infinitely more complex. Above all we need to ensure that we integrate technological solutions with psychosocial interventions.

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The afternoon session was concluded by Brian Lamb who made the case for extending access to adult cochlear implants and reviewed the evidence for a radical revision of the current NICE guidelines. He looked at the way in which the potential benefits of cochlear implants are currently assessed and made the case for a wider review of commissioning arrangements and support.

At a second event following the main conference Lillian Greenwood MP formally launched the report **'Adult Cochlear Implantation: Evidence and experience - the case for a Review of provision'**,

prepared jointly by Brian Lamb and Sue Archbold. This report reviews the current evidence on the impact of deafness in adulthood and the new evidence of the impact of cochlear implantation in adulthood since the review by NICE. It maps the provision of cochlear implantation in England in a changing health context. It also reports on new research exploring the experiences of adults who have been refused implantation. The report goes on to make a number of recommendations all of which are fully endorsed by NCIUA who are working closely with the report authors to help improve the provision of cochlear implants for adults in the UK.

Cochlear implantation around the world

A series of articles in the current number of Cochlear Implants International, the journal of the British Cochlear Implant Group, reveal some surprising facts about the take up of cochlear implants in two of the most developed countries in the world.

USA

In the USA only a small percentage of the population who could benefit from an implant actually receive one. Around one to 1.5 million children and adults have a severe to profound hearing loss and are potential candidates for cochlear implants but only 100,000 children and adults have actually received one. This means that only 5-6% of those who could benefit from an implant actually have one. The author concludes that this is due to the lack of accepted 'best clinical practices', the opposition of the deaf community and lack of accurate information about implants. *Cochlear implantation in the world's largest medical device market: utilisation and awareness of cochlear implants in the United States, by D L Sorkin.*

To improve the situation and promote cochlear implants a new organisation has been founded – the American Cochlear Implant Alliance Foundation.

Japan

In Japan the situation is worse. The uptake rate is only 1% of potentially suitable candidates of all ages. In the case of children only 3-4% under the age of three are being implanted at less than 18 months of age. This partly due to there being significant problems with the neonatal screening programmes in various part of the country. *New expectations: paediatric implantation in Japan, by J. Oliver*

China

In China, which has a rapidly developing economy, the number of potential cochlear implant candidates is huge but the number of people with cochlear implants is low. There are improvements. By 2010 a universal hearing screening programme had been implemented in 20 of the 32 Chinese provinces and in large cities 95% of babies are screened in hospital based programmes. A national reimbursement scheme for medical care is also being developed. The government set up a scheme to implant 1500 children in 2009 and agreed to fund a further 17,000 in 2011. Although currently less than 5% of children who could benefit from and implant have one cochlear implantation is expanding rapidly and the next few years will see many changes. *Enter the Dragon – China's journey to the hearing world by Q Liang and B Mason.*

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By contrast in the richer European countries cochlear implantation is well established though there are variations. In the UK the 2011 figures show that 74% of eligible children aged 0-3 years had implants and 94% by the age of 19. However only 5% of the eligible adults actually have one. The reasons for this are the lack of awareness among both candidates and professionals. Another reason is the criteria for implantation laid down by the National Institute of Clinical Excellence (NICE) are stricter than in some other European countries. *Cochlear implantation in the UK: awareness and utilization by C Raine.*

Belgium is one of the leading countries in cochlear implantation. It has been a centre of excellence in cochlear implants for many years. The Belgian National Institute for Health and Disability Insurance has reimbursed cochlear implants in children and adults since 1994 and bilateral implants in children since 2010. By 2010 93% of severely or profoundly deaf pre-school children had received implants and 25% had bilateral implants. The situation in respect of adults is less clear but on average twice as many adults as children are implanted each year in Belgium. *Accessibility to cochlear implants in Belgium by L D Raevé and A Wouters.*

The Ear Foundation

Hearing & Communicating in a Technological Era



Sound Advice Adult Days 2014

Helping adults make the most of their hearing technology

These group days give adults, their partners and friends the opportunity to meet up with time to talk on a range of topics. They are run by experienced professionals who can offer friendly help and up to date advice. Adults are also able to visit our **Resource Centre** throughout the day for hands on advice.

Balance

Saturday 1 February (10:30am till 3:00pm)
How our ears are involved? Hosted by Andrew Clements, Physiotherapist, The London Road Hearing Clinic.

Communicating with Signs & Finger Spelling

Saturday 22 March (10:30am till 3:00pm)
Learn more about signing and finger spelling with Helen Starczewski, Speech and Language Therapist

Music

Saturday 10 May (10:30am till 3:00pm)
Come and join us for our music workshop, where we will be joined by a variety of musicians.

BBQ

Saturday 5 July (3:00pm till 6:00pm)
Come and join us for our annual BBQ, in Normanton on Soar, where there will be lots of stalls, games and food, everyone welcome!
Lunch and refreshments available, £10 per person

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 Rehabilitation 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. For 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
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Hearing Link

Manufacturers' News

From Advanced Bionics

Rehab Apps for Adults and Assessment Apps for Children: New iPad apps help adults hear with cochlear implants and professionals assess hearing in young children

Advanced Bionics (AB), a global leader in cochlear implant technology and a company of the Sonova Group, has launched two sophisticated iPad® apps, designed to help adults learning to hear with cochlear implants and hearing professionals working with children.

CLIX is the first instalment in a suite of rehabilitation applications that make up the Advanced Bionics Listening Exercises (able). Cochlear implant systems are frequently referred to as technological miracles for being uniquely capable of restoring one of the human senses, the ability to hear. Recipients of this life-changing technology find that their hearing can improve with practice. The free CLIX app is designed to help adult cochlear implant recipients practice listening for word differences in both quiet and noise. It can also be used by adults with hearing aids.

"Rehab is an essential component of the journey to hearing. AB is taking advantage of the great platforms that popular mobile devices provide to put helpful new rehab programs right at your fingertips," said Hansjuerg Emch, Group Vice President of the Sonova Medical Division within which AB resides. "AB is committed to providing industry-leading support services. The CLIX app is a perfect example of that dedication."

The second app released from AB, IT-MAIS, is a version of a popular assessment tool used by professionals around the world to evaluate a young child's response to sound during their first few years of listening with hearing technology.

"Early intervention in addressing hearing loss is crucial, and assessing young children is particularly challenging," said Carissa Moeggenberg, Education, Training and Rehab Manager at AB. "We believe the IT-MAIS app will lead to more children being assessed early and accurately, so that we can provide them with the technology that will help them develop language skills earlier and excel in mainstream schools alongside normal-hearing peers."

Both apps are compatible with the iPad tablet and are available now for download in iTunes store.

My Naída CI Q70 Experience

"It's great and I like it! I was very pleased with my Harmony™ processor previously, but the Naída CI Q70 is a big step forward in AB's development programme."

The key difference is that the overall sound quality is better; it's fuller and clearer and louder. There's more top (higher frequency perception) and I think some more bottom. The sound is more alive and sounds like it has been unmuted. The top most notes of the piano are now heard as a sound rather than a click even though the receptive pitch range has not been changed from AB's standard 250-8700Hz."

Richard Byrnes, Naída CI Recipient

For more information about the Naída CI sound processor or Advanced Bionics, contact a local AB representative, visit AdvancedBionics.com or email info.uk@advancedbionics.com

From Cochlear

Hear, there and everywhere Making travel plans easier

The Cochlear™ Travel Programme

The Travel Programme gives Nucleus™ cochlear implant recipients peace of mind when away from home. Whether travelling for work or relaxing on holiday, damage or loss of a sound processor(s) need not ruin a trip.

You may find it worrying for you or your child to be without a sound processor(s) at any time, but much more so if you are working abroad or away on holiday. The Cochlear™ Travel means you don't need to worry about finding a local clinic for a replacement or for you or your child to spend the rest of your trip in silence. With three plans to suit the needs of different travellers, we've got you covered. You just need to decide which plan suits you or your family best and let us know where and when you are going.

Annual Cover Plan: *Our best value plan – ideal for those who travel more than once a year*

There is no need to make special arrangements each time you go away. With our Annual Cover Plan, it doesn't matter how often you travel or how many different destinations you visit. If you or your child lose or damage a sound processor(s), we will ship a temporary replacement(s) to you as quickly as possible. That's one thing less to worry about when you are planning a trip. Family option – for a nominal additional fee you can extend this cover to include all Nucleus recipients in your family.

Single Trip Plan: *Perfect for occasional holidays and travel*

Don't risk your holiday being spoiled or your

business trip being cut short. In the event of you or your child losing or damaging a sound processor(s), we will ship a temporary replacement to you to ensure you or your child is hearing again as quickly as possible. Family option – for a nominal additional fee you can extend this cover to include all Nucleus recipients in your family.

Full Backup Plan: *Designed to ensure you or your child won't miss a moment of your trip*

Sometimes you can't even afford one day without you or your child hearing. Or perhaps you are travelling to an exotic location where our courier can't reach you. With our Full Backup Plan, we will send a backup sound processor(s) directly to you before you leave home. You can then enjoy your trip, knowing that you or your child has a replacement sound processor(s) immediately available if needed.

To find out more about the service and request a leaflet, please contact your cochlear implant clinic or Cochlear Customer Services:

Email uktravel@cochlear.com or telephone 01932 263 640 or

visit our website www.cochlear.com/uk

From MED-EL

MED-EL Sports Headband – Ready for your active life!

Good news for sport lovers – MED-EL has teamed up with renowned sportswear producer skinfit® to bring you the MED-EL Sports Headband, designed for your comfort and security during sports and other vigorous activities.

The MED-EL Sports Headband features specially designed pockets that keep your Amadé or RONDO audio processor securely in place over the implant during various activities and is suitable for bilateral users.

The breathable microfibre material design protects the audio processor from sweat and moisture, providing maximum ventilation for user comfort, while flat seams ensure a comfortable fit. The material is also odour-resistant and thermo-regulating. The MED-EL Sports Headband should not be used for water sports.

The headband is black and is available in four sizes (XS, S, M and L). Headbands are now in stock and can be purchased from the MED-EL UK Shop, simply email orders@medel.co.uk

For more information about the MED-EL Sports Headband, visit: medel.com/sports-headband.



Message from the Editor

I have just finished reading 'I am Malala: the girl who stood up for education and was shot by the Taliban'*. It is a fascinating story and I am now much better educated about the Taliban and its origins than I was. Many people know that Malala is now a cochlear implant user. Although the loss of hearing in one ear is but one of the injuries that Malala sustained I was fascinated by her awareness of what one sided hearing loss meant. After her severed facial nerve had been repaired (I didn't know this was possible!) she was discharged from the Queen Elizabeth Hospital, Birmingham. She records going for a walks with her parents but in a crowd she could not understand what they said. And 'inside my ear was a tinny noise which only I could hear.'

After her traumatic experiences she concludes her story with gratitude to God for all he has given us – two eyes to see with, two feet to walk on, two hands to work for us and finally 'two ears to hear the words of love. As I found with my ear, no one knows how much power they have in their each and every organ until they lose one.'

We are very grateful to the manufacturers and others who have supplied news and information for this issue of the Newsletter but we always welcome input from our members and CI users. The deadline for the Spring edition is 10 April.

*Available as printed or kindle book from Amazon.

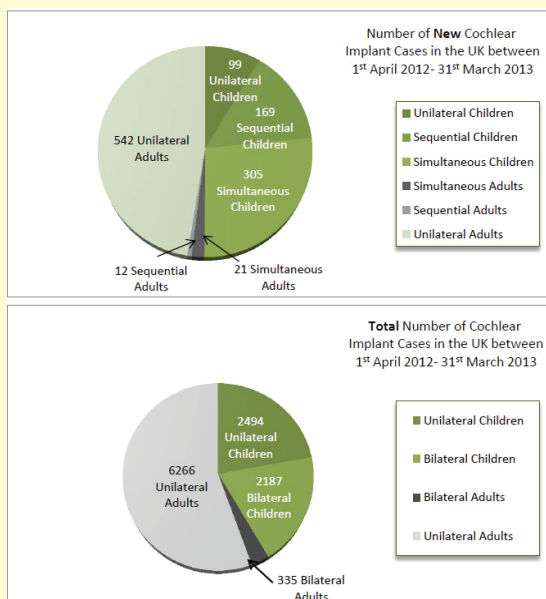
Your Help is Needed on a Research Topic

Can you help with some important research that has just started at the University of York?

We all know that some of us cochlear implant users find it challenging to work out where a sound is coming from whereas other users find it is quite simple. Adel Goman's research project is to investigate these differences and identify how people localise sound in quiet and when other sounds are present. Adel is a PhD researcher within the Department of Psychology which is headed by Professor Quentin Summerfield who has given us so much support during his own research on cochlear implants.

Volunteers would need to travel to York to take part but expenses by rail, car and taxis will be refunded and, for those travelling from afar, the costs of accommodation will also be covered with a subsistence allowance. If you wish to travel with a companion those costs will be covered as well.

If you are able to help, please apply contact Adel (email: ag562@york.ac.uk or phone 01481 322879) for further information or to answer any queries you may have.



We are grateful to BCIG for permission to reproduce this chart.

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Disclaimer

Whilst the Association uses its 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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