

Newsletter

NATIONAL COCHLEAR IMPLANT USERS
ASSOCIATION NEWSLETTER



Cochlear Implants 2009



From left to right Dr Bernard Seiber, Chris Bones, Richard Byrnes, Louise Craddock, Sandra Driver, John Atkins, Dr Patricia Chute, Steve Sharp, Dr Connie Mayer, Lindsey Evans, Mr Emanuel Mylanus. (Photograph courtesy of the Ear Foundation)

State of The Art

The Ear Foundation held its 4th annual conference on the State of the Art of Cochlear Implants at Nottingham on 13th November 2009. Introduced by John Atkins, Chair of The Ear Foundation, an international panel of speakers discussed a wide ranging review of topics to a large audience of professionals and they were presentations from Dr Patricia Chute (New York) on current challenges, from Dr Bernhard Seiber (MRC Hearing Research) on bilateral and bimodal implantation, from Mr. Emanuel Mylanus (Holland) on the surgical

challenges in implantation and from Steve Sharp (NHS Library) on the ENT Specialist Library.

There were also presentations from Chris Bones (Nottingham) on complex paediatric case studies, from Lindsey Evans (GOSH) on psychological outcomes and Dr Connie Meyer (Toronto) on literacy development in deaf children following implantation.

The presentations by Louise Craddock (Birmingham) on the Challenges facing CI teams in the UK and Sandra Driver (Guys & St Thomas') on Communication will be published in the Spring 2010 edition.

New Look

Readers may notice some changes to the look and layout of this Newsletter. It was decided that the new decade of the Twenty-Tenies (after the, Eighties, Nineties and the Noughties) should be marked by change so the Newsletter has been given a makeover to help it progress in the future. So what do you think? What other changes might you wish in style and or content?

All comments will be welcome.

Editorial - Adult Rehabilitation

Nigel Williams, our Chairman, was originally invited by The Ear Foundation to give a presentation on cochlear implant users experiences at the State of the Art convention in Nottingham on 13 November 2009 but due to his indisposition at short notice, your Editor, Richard Byrnes, gave a personal presentation on Adult Rehabilitation which is summarised here.

The growth in implant figures in recent years has featured a steady increase in the number of child implants arising from the Neonatal program and now reinforced by the NICE recommendations on bilateral implants for children. The Association fully support this development but it should be noted that adults still represent half of the workload of implant programmes across the UK and that the needs of adults on rehabilitation still require full consideration. With the shifting demographics of the country's population and the increasing numbers of the older generation, the needs of adult potential candidates and users will continue to feature strongly in the future.

The issues of the variability in the outcomes of implantation were reviewed and it is important to recognise that rehabilitation itself could be a contributory factor. Despite someone being a very suitable candidate, having an uneventful and successful operation, being successfully fitted with a device and properly mapped, a poor outcome could still arise from inadequate or insufficient rehabilitation. Rehabilitation is the end process of a CI programme whereas for candidates/patients it is the beginning of a new life and these users need full and continued support to learn how to adjust to their completely new hearing experience and cope with their new environment. Regarding user experiences a number of questions concerning rehabilitation arise. As users are we expecting to little? Do we expect too much? And as regards the overall outcome experience - Is this as good as it gets? Do we achieve our full potential?

Reflecting on the conference theme- State of the Art, it is acknowledged that in terms of surgery and implant device technology those areas are currently at the leading edge but it is questionable whether rehabilitation as a subject itself is that far advanced.

Rehabilitation Therapy

- To maximise the benefit of cochlear implantation
- To ensure a satisfactory outcome
- To focus on patient objectives

Fig 1

(The basis of rehabilitation therapy and objectives are set out in Figures 1 & 2).

Adult Rehabilitation Objectives

- To give information about the device
- To provide training in speech perception
- To monitor speech and voice production
- To maximise communication strategies
- To ensure that the device can be used effectively

Fig 2

Is there a uniform structure and content of rehabilitation across all adult programmes? What procedures or protocols exist? The BCIG Draft Quality Standards, dated June 2009 quote two specific standards for rehabilitation and set out minimum levels of treatment (see Figure 3). This development is very welcome and hopefully it will be adopted throughout.

Rehabilitation Structure

- Draft Quality Standards for Adults CI Implantation June 2009
- QS. Sufficient rehabilitation sessions should be offered to optimise cochlear implant use
- QS. Standardised audiological and speech perception measures should be performed on at least two occasions in the first year following surgery.
- Frequency – 6 sessions in year 1
- Duration - 4 years

Fig 3

Yet more needs to be done. There should be more research on the subject of rehabilitation not just on its outcomes but on its technology and procedures. The formation of the National Biomedical Research Unit in Hearing (NBRUH) in Nottingham in March this year is a step forward but it is important that all professionals give more attention to the subject.

Recognising the increasing workloads on implant teams, it could help ease these matters if CI staff moved to devolve as much as possible of the issues concerning the implant devices themselves onto the manufacturers. CI Centres should call upon the manufacturers for substantial and continued support not only in the areas of access to CI users for advice to candidates but especially in rehabilitation support materials, in auditory training support and for interactive troubleshooting support.

Many of these personal views are credible because in quoting from as yet unpublished draft results of a survey on adult rehabilitation conducted by the Ear Foundation, there is an overwhelming call by adults for more rehabilitation, together with the need for more local support at local audiology units as well from the implant centres themselves.

In conclusion Richard Byrnes thanked The Ear Foundation for the opportunity to present a users view to an audience of professionals and further expressed his thanks, on behalf of the Association's members and all implant users, for the professionalism, dedication and hard work of all the staff in the cochlear implant programmes in the UK.

News from Westminster

by Ray Glover, NCIUA Secretary

The All Party Parliamentary Committee on Deafness, under the chairmanship of Malcolm Bruce M.P., met with members of UKCoD, the United Kingdom Council on Deafness, at the Houses of Parliament on 1st December 2009. The meeting was attended by six members from both Houses and UKCoD representatives who listened with interest to presentations on two topics where UKCoD felt changes needed to be made. .

Bert Smale from the Association of Teachers to Lip-reading Adults explained the importance of lip-reading classes to people with hearing loss, particularly those who had suddenly lost their hearing. He explained how, when the current arrangements for funding adult education were put in place, lip-reading classes had been classified with languages, such as holiday French. This meant that local authorities were obliged to charge economic fees for the classes and could cancel those which did not have sufficient support. This threatened the future of classes because individuals were not seeking training to be teachers due to the uncertain prospects of employment. In summing up Malcolm Bruce seemed to accept that lip-reading classes should be part of rehabilitation for deafened people. We will have to wait and see if the necessary changes are made to bring this essential provision within the realm of the NHS.

The second presentation was from Raena Raja, a parent of a deaf child who has a cochlear implant. She explained the difficult choices facing parents, particularly hearing ones who make up 90% of families with deaf children. She illustrated, through her own experiences, that communication between parent and child was paramount. This was something very personal within the family and would change as the child developed. Choice should be supported across both health and educational provision. She highlighted the unevenness of the availability of sign language teaching across the country, particularly of classes aimed at parents who needed to learn sign language appropriate to the needs of a young child and not that of adults. Speakers from the floor made strong pleas that deaf children had a right to learn to sign and so have the choice to be a member of the deaf community. Others pointed out the right of the child to be fully included in the hearing world, in communication with all the family and friends who most likely would be hearing. This, of course, is a debate that has gone on for over a hundred years and is not one, in my view, that has a right or wrong resolution. What matters is that the quality of provision be of the best and that the child's changing needs are catered for. Malcolm Bruce shared with us that his daughter, now age 31 was deaf and he had first hand experience of the problems faced by a parent.

Hearing Matters



Emma Harrison

A major conference was held by the Royal National Institute for Deaf People (RNID) on the 29th November, 2009 at the imposing venue of the Royal Society in London. Located on Carlton House Terrace, overlooking the Mall and close to St James's Palace -an ancient area of London, the Royal Society is celebrating its 350th anniversary as the National Academy of Sciences. This august Society whose members include such famous people as Isaac Newton, Captain Cook, Crick and Watson and Steven Hawkins was a fitting venue for the RNID as it continues to push the boundaries on hearing matters. The RNID itself is soon due to celebrate its 100th anniversary.

Welcoming a large audience Jackie Ballard, Chief Executive, reminded us that deafness was not a popular cause despite the fact that for so many it made life quite miserable. In speaking of a number of her own experiences contacting people with a hearing loss, she spoke of the unfortunate few who felt so isolated and their confidence so debilitated that suicide had even been contemplated and yet there was such inspiration from examples of Janine Roebuck, a newly elected Trustee who became deaf as a teenager yet now has a full career as an opera singer! (Janine will be focusing on the RNID's award winning Don't Lose the Music campaign - see www.dontlosethemusic.com).

Whilst the often quoted fact that there 9 million people in the UK with some form of hearing impairment is disturbing, the more distressing fact was that this figure will rise by 40% over the next 30 years as the aging shift in the population progresses. Another remarkable fact is that for those whose hearing loss is a gradual event, it is known that it can take an average of 10-15 years for some people to do something about trying to improve their quality of life and this puzzle in fact was one which the RNID intends to address in its future plans

The RNID is moving forward on three broad themes (see figure 1)

RNID's Objectives

- We seek to **CHANGE** peoples behaviour so that they seek early help for any hearing loss & to avoid exposure to loud noises and loud music.
- We seek to **CONNECT** with people with a hearing loss and give them full support.
- We seek to **CURE** hearing loss by investing in research as to its causes. *Fig1*

Emma Harrison, Director of External Affairs, spoke of their plans on taking action on hearing loss. Individuals often only acted because they were forced to by life changes. Because hearing loss is not life threatening it is often known as the hidden disability and this could be a reason why people take so long to act upon finding a solution or help and support in conducting their lives with a hearing loss. Though it is not life threatening it is unquestionably very much a lifestyle threat to an extent that some people even go into denial. It is estimated that there are 4 million people in the UK who should have hearing aids and have yet to seek help in this direction and there are tens of thousands of people who would benefit from a cochlear implant but similarly have not done so.

Continued on page 5

The issue of cosmetics are often raised and yet why should people be disturbed by the appearance or presence of a hearing aid or cochlear implant? Compared with the typical 10-15 year delay in seeking help with hearing loss, on average people only spend up to 3 years in seeking treatment for vision difficulties and getting eye glasses. Everyone is used to seeing people in eye glasses and for that matter used to seeing people with walking sticks or crutches or in wheelchairs so why should people be concerned about being seen with a hearing aid or cochlear implant?

Turning to government support Emma called for a national hearing loss screening program for the over 55s. It would make sound economic sense to help people live full and productive lives. Everyone is already eligible for free eye tests at the age of 60 and for free dental check ups at 65 so why not a hearing loss check? In conclusion Emma described of plans for a resurgence of local action and campaigns to increase the awareness in the public generally of hearing loss and its impact on people

Mike Anderson, Director of Internal Services, said he had a passion for a level playing field for all people concerning anything to do with their physical or mental abilities. Why should the deaf settle for a reduced quality of life he argued and spoke of the RNID theme- Keep Connected- in order to help people with a hearing loss get closer to the services that would help them. Much effort and attention has very properly been given to the problems of the physically disabled yet it was only fair that the hearing disabled should receive similar levels of support. In this respect RNID had a program of help, run by its own volunteers together with drop-in clinics around the country where hearing loss sufferers could get advice and help. There is also a specialist support team for those who had other disabilities beyond hearing loss and thus presented more complex problems. Finally there was the RNID Solutions catalogue and RNID Shop which can supply a very large range of equipment and accessories to help hearing loss people live more independent lives.

Professor Matthew Holley, The University of Sheffield, spoke on their large programme of

biomedical research, in part funded by the RNID. He stated that the economic cost of hearing loss in the UK was an astounding £13.5 billion and yet only 2% of the medical research budget in the UK was spent on hearing loss matters. Against a background of 250 million people worldwide with the hearing loss, Professor Holley reviewed the factors which contributed to or caused hearing loss and of the programmes that were being researched to try and trace these causes and their treatment. He spoke of research into drugs to help mitigate the onset of hearing loss caused by the ageing process, of drugs to counteract neurodegenerative diseases, and of gene therapy treatment using stem cells to rebuild hair cells in the cochlea. He paid tribute to RNID for funding a 3 year research project and noted that the RNID was funding 12 programmes worldwide on research into hearing loss and its possible prevention and treatment.



Letters & Emails

I was very pleased to be able to publish two letters in the Autumn edition. Yet I rarely get letters or emails to publish which is a shame as it helps others if we raise matters of interest and/or discuss topics which may concern us all. So in future there will be a prize of £5 per edition on offer for the best letter or email received. It doesn't have to be about an article in a Newsletter although they may stimulate responses. In this edition, you are particularly invited to comment, separately, on 2 themes. The Editorial on Adult Rehabilitation (see page 2) and New Look (see front page)

Ed

Twilight Lecture



Dr Patricia Chute

This year the Marjorie Sherman Memorial Lecture at The Ear Foundation was given by Dr Patricia Chute, Dean of Mercy College, New York, on the subject of cochlear implant conundrums.

Is it the map, the equipment, the services or the user?

The success of any cochlear implant user is a result of a multiplicity of factors that contribute to the overall outcome. This is particularly unique in respect of implanted children where all these factors can influence the inherent ability of a child to demonstrate interaction with each on performance. Pre implant characteristics and audiology history have a major bearing on post implant responses. Psychological issues and the level of intervention by parents and professionals play their part.

So often parents, in their concern for the progress of their child's hearing, ask for repeated re-mapping. There are currently difficulties in establishing correlation of performance with mapping so this can be a circulatory activity. Minor equipment issues can often have a bearing on performance such as low battery power levels and contamination of microphones which need cleaning and these issues need to be resolved before re-mapping.

The rehabilitation progress process itself can be uneven. How much is required to achieve a satisfactory outcome? And when should it stop? It is unquestionably true here that more is always best and whilst professionals may have time limits imposed on them by resources, the child and parents need to be pursue their goals over a long period of time.

Dr Chute quoted the Malcolm Gladwell theory that it takes 10,000 hours for a sports person to achieve excellence and become a professional. This is may seem an extreme figure for adults let alone children but it illustrates the need for all users to continue to work at their rehabilitation whether or not they are supported by professionals.

WEST LONDON COCHLEAR IMPLANT SUPPORT GROUP

This new group was set up in February 2009 by Lidia Best to provide peer support and practical advice with social activities for people from all walks of life who share life with a hearing loss. The group, which consists of both cochlear implant users and partially hearing people whose usual means of communication is speech, is part of DeafPlus in Acton, the Hard of Hearing Club. **For more information see www.westlondonci.webs.com**

They are actively working with the International Federation of Hard of Hearing People, which is a powerful voice on all International and European platforms and will be participating in the IFOHOH (www.efhoh.org) Young Peoples Summer rally in Switzerland in July 2010

Partnership

This year Hearing Concern LINK did not hold its annual convention in London in October having been advised that it might not be appropriate in view of the swine flu epidemic risk. Instead they held three regional Partnership events, one in Glasgow, one in Wales and one in West Sussex.

The Scottish event was held in conjunction with the Scottish Council of Deafness and the Welsh event with the North Wales Deaf Association.

The southern regional event was held at Haywards Heath in West Sussex on the 28th November in conjunction with Action for Deafness. Lorraine Gailey, CEO Hearing Concern LINK, welcomed the audience and introduced a review of the oral history project organised earlier this year in conjunction with the British Library. (This was reported in our Autumn Newsletter in an article entitled Unheard Voices). They have now produced an education pack entitled Unheard Voices which features a DVD of interviews with deafened people with articles on acquired profound hearing loss (APHL), what



causes hearing loss together with communication and technology work sheets. This pack is available free on application to their offices (19 Hartfield Road, Eastbourne, BN21 2AR) and is intended for use in schools, hard of hearing groups, in deaf clubs and for information and support at home. Jane Shaw, CEO of Action for Deafness, and herself a cochlear implant user, explained how her organisation now provide a contract service to the NHS across the whole of West Sussex for adult rehabilitation audiology for the over 50s and the meeting concluded with a presentation by Gill Houghton who gave some valuable insights to the technique and benefits of lip reading.



'Deaf' toddler enjoys sound of Christmas after getting 'bionic' ears

A toddler enjoyed the sound of his Christmas presents for the first time after getting "bionic" ears. Harvey Minto, now two, was diagnosed as deaf shortly after he was born. But after cochlear implant surgery four months ago, the youngster has been making a lot more noise and can now "hear" sounds around him. His mum, Lyndsay Mascoll, 19, from Sunderland, said: "It has been a difficult two years but to see Harvey making such huge progress is amazing." Lyndsay added: "He is a different child now."

Courtesy of The Mirror Co UK

DIARY DATES Summer Meeting & AGM - Saturday 12th June 2010 - London

GROUP NEWS

MANCHESTER

16 January 2010 A group outing to Martin Mere WWT: Burscough, Lancashire L40 0TA.

27th March 2010 Manchester Cicada Club AGM and Conference.

Information for both events available from secretary@manchestercicada.org.uk

HOME COUNTIES GROUP

New Support Group Meeting 1st Wed each month

36 Brigadier Hill, Enfield, Middlesex

19 Jan Coffee Bar

16 Feb & 11 May 2010 Wine Bar at Brookes Brothers 33-35 Brooke Street Holborn.

For further information please see - www.hccig.org.uk

SOUTH WALES GROUP

30 Jan 2010 Christmas Lunch

The AGM will be in May and the Summer BBQ in July-dates to be advised later

For further information please email - doreengunning@dsl.pipex.com

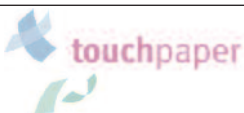
SOUTHERN BIONICS BUDDIES

5th June 2010 Summer Meeting

For further information please email - elainebilateralci2007@yahoo.co.uk

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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We wish all members and readers a very happy, healthy and good hearing New Year

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