



Supporting Deaf Adults

Nigel Williams (Cardiff) – UK's 412th Point of Light award

A Cardiff volunteer who has supported deaf adults both emotionally and practically through establishing support networks and rehabilitation programmes.

Nigel Williams, 59, was inspired to support adults with hearing loss and their families after becoming deaf at the age of 16, due to meningitis. Nigel believed that more could be done to assist the hearing impaired and wanted to use his personal experiences to help adults cope with the impact of hearing loss.

Nigel is currently the Chairman of Hearing Link, a leading UK charity tailored purely to helping adults and their families cope both emotionally and practically through a support network of volunteers. Nigel has volunteered at Hearing Link for over 12 years and, under his steer as chairman, the charity has grown and developed ways of helping all those who rely on them. Hearing Link offers a wide range of services including a Self Management Programme and a weeklong Rehabilitation Programme where participants receive practical support in dealing with hearing loss delivered by volunteers who themselves have experience of living with hearing loss. In addition to these programmes Hearing Link provide one to one community sessions and an online support forum supported by volunteers.

Nigel's work has led to many users of the charity becoming volunteers themselves and giving back to others. Nigel is also the Chairman of the association that represents people who rely on cochlear implants, electronic devices that replace the function of the damaged inner ear allowing people to hear. The National Cochlear Implant Users Association works to improve awareness of the support that is available for people needing the implants. As Chairman, Nigel set up effective partnerships with support groups, including with the three UK's most influential charities for deafness. Together they have changed the



standard treatment for deaf adults in the UK, raised awareness and given evidence to government to ensure that cochlear implants are now regarded as a standard method of treatment when an adult becomes deaf, regardless of cost.

Prime Minister David Cameron said:

"By bringing together two of the biggest charities working with deaf adults in the UK, Nigel has made a huge difference to the services and support available to them. He has also played an important role in making sure the guidance given to the NHS on treatment for deaf adults offers them the highest standard of care. I am delighted to recognise Nigel as the UK's 412th Point of Light."

Nigel Williams said:

"I am surprised and thrilled to receive this award which I hope will encourage everyone who is dealing with hearing loss, which often impacts on far more than your ability to hear. The consequences of hearing loss often affects a person's confidence and self-esteem and through practical support from people who live with hearing loss themselves people soon see

DIARY DATES

6th June 2015 Summer Meeting and Annual General Meeting will be held at the University of London (Birkbeck Main Building), Torrington Square, London WC1E 7HX. Watch the website for more up-to-date information: www.nciua.org.uk

that this need not be a barrier to leading a full and rewarding life. It's a privilege to work with an organisation such as Hearing Link and I am grateful to everyone involved who provide so much help and support to others."

Stephen Doughty said:

"Congratulations to Nigel, a thoroughly deserving recipient of this award. He has used his own

personal experience to help so many people with hearing loss, providing support and advice to help them live well and overcome the challenges they may face. His determination to improve the lives of others is an inspiration."

The daily Points of Light award recognises outstanding individual volunteers - people who are making a change in their community.

Bending The Spend: The Economic Impact of Hearing Loss

This was the subject of a new report by Sue Archbold, Brian Lamb and Ciaran O'Neill which was published on 13 Oct 15 at the conclusion of a conference held in London organised by The Ear Foundation. Lillian Greenwood, MP (Chair of the All Party Group on Deafness -at that time), officially launched the report at a reception in the Churchill Room of the Houses of Parliament, Westminster. This report is the third in a trilogy of reports on the costs of ignoring adult severe hearing loss compared with the actual cochlear implantation costs themselves. The second report, *The Real Cost of Adult Hearing Loss*, was reported in our Newsletter No. 60 Winter 2015. It concluded that savings of £30 billion were estimated and this economic burden is such that mitigating even a proportion of sum is likely to yield significant benefits.

All three reports can be downloaded from <http://www.earfoundation.org.uk/news/articles/493>.

This latest report developed the ongoing theme of the impact of adult hearing loss to further demonstrate the huge economic cost and social consequences of not providing cochlear implants to all severely deaf adults. The statistics compiled are staggering. One in three adults over 65 have a hearing loss. At least 1 in 10 adults aged 40 to 69 have a substantial hearing loss. Adult onset hearing loss is among the top ten disabilities in terms of years lived with disability for those over 60. The World Health Organisation estimates that in the UK adult onset hearing loss will be in the top ten disease burdens, above that of diabetes! Those with untreated severe hearing loss are at five times the risk of developing dementia as those with normal hearing. Unemployment rates for people with hearing loss are much higher compared with the national average with 30% of people of working age with severe hearing loss being unemployed. Recent estimates suggest that the UK economy loses £25 billion a year in productivity and unemployment due to hearing loss.

Several important recommendations were made. Foremost was that as part of the



Sue Archbold, Brian Lamb and Ciaran O'Neill

implementation of the Government's Action Plan on Hearing Loss, the NHS should ensure that there is a review of the current specialist commissioning criteria for cochlear implants working in collaboration with users under the principles of co-production. Next that NICE should review its current (2009) guidance on cochlear implants, both for unilateral and bilateral implantation, to take account of the real world benefits and the additional costs of untreated hearing loss. Further that the NHS, working with the audiology, medical professions and users should develop a targeted programme to promote greater awareness of the benefits of cochlear implants for GPs and other health professionals including the importance of early intervention and integrated planned support as part of the Action Plan in England. Also that Audiology professionals and related services should have the training and support to ensure that they can properly identify and refer those who could benefit from a cochlear implant.

Richard Byrnes

A Brief History of the Gloucestershire Cochlear Implant Group

Last November Gloucestershire Deafened and Cochlear Implant Support group celebrated 10 years of supporting deafened adults by holding a party at Gloucester Deaf Centre.

I had been profoundly deaf for about 15 years before I seriously thought about having a CI. I had never met another CI user and the only knowledge I had about CI's was from reading articles in deaf magazines. My first visit to Southmead was in March 2001. Once I was going through the assessment programme I was invited to a couple of meetings at Southmead. Here I had the opportunity to meet people who had CI's, to hear about their experiences of the operation, rehabilitation and the impact that having a CI had on their lives in general. I was introduced to a lady called Sylvia who had received her CI about a year earlier. It was extremely helpful to be able to speak to a recipient, face to face, and to ask the many questions about the whole CI package that I had. The meetings included talks by the CI manufacturers about their products and also the personal experiences of CI recipients. I found these meetings invaluable in terms of helping me to make a decision about whether, or not, to have the operation.

In June 2003 I received my CI at Southmead, Bristol. After having my implant I felt there was a need for a local group where prospective CI candidates and their partners could meet people who had CI's, ask them questions and generally find out more about the whole process before being referred to Bristol or Birmingham. I approached Hearing Services with this suggestion. Joanne Dutton, who had recently joined Hearing Services as a Hearing Therapist, was also very interested in cochlear implants and the need for a support group, so with financial and administrative support from Hearing Therapy and with Joanne at the helm, GCISG was started in 2005. It was stated from the start, that once the group had 'found it's feet' it should be run independently by its members but with close links to Hearing Therapy for professional patient support and referrals.

For the first 5 years the group met twice a year at GDA. These meetings tended to follow the format of the ones at Southmead. Group members told their personal CI stories, there were visits from CI representatives and other 'deaf' organizations. We also met for a social pub lunch once a year. An email group was established. This was used to inform members of meetings, to offer advice and support and to pass on useful information about general deaf issues. We had a bi-yearly newsletter, funded and compiled through Hearing Therapy.



A barbecue in a member's garden

In 2009 the group was transferred into the hands of its members and Bob and I took over the reigns as joint chair with Joanne taking a step back but still keeping a supporting role.

By this time, the number of CI operations being performed was growing rapidly and information was becoming easily accessible on the web. Bob and I decided to ask members what they wanted from the group. It became apparent that the majority of members wanted the opportunity to meet more often socially and get to know one another better. To this end we began to have monthly social meetings. Pub lunches, walks, visit to places of interest, plus one formal meeting a year at GDA which included our AGM and a speaker from a deaf organization.

In 2010 it was decided that we should welcome into the group any deafened people who, for whatever reason, did not have, or did not meet the criteria for a CI as we all had very similar needs in terms of communication and personal support. Apart from being able to exchange information and personal experiences about having and living with a CI the group has given all its members so much more. As we all know, becoming deaf as adults is both depressing and isolating. Spending time with others who are "in the same boat" can be uplifting as we realize that we are not alone. Friendships have developed between deaf people who would never have met. We know that there is always someone ready to listen, and also to give us support and help if we need it. As our group has grown and flourished it has enriched all our lives.

Cathy Hopkins

Editor's note: Information about other regional support groups can be found on our web site: www.nciua.org.uk

Manufacturer's News

From Advanced Bionics

Advanced Bionics Certified Retail Partners

Advanced Bionics (AB) is pleased to announce the launch of AB certified retail partners in the UK and Eire. AB recipients, their family members and friends can now purchase AB



Advanced Bionics

products and accessories directly from independent hearing aid dispensers on the high street. AB certified retail partners are hearing healthcare professionals with specialised product knowledge and high levels of customer service, meaning they are able to deliver the professional expertise and aftercare required for cochlear implant users.

AB has carefully selected retail partners across the UK and Eire to make the services accessible to as many AB cochlear implant recipients as possible. AB's partners sell a wide range of AB products and accessories including the waterproof AquaCase™ enclosure for the Naída CI Q70 processor, batteries and cables, and a range of Phonak AB compatible products including the ComPilot accessory, TVLink II accessory, and the Roger system.*

These are the contact details of all AB certified retail partners in the UK and Eire:

- Pindrop Hearing, London www.pindrophearing.co.uk
- Help in Hearing, Buckinghamshire www.helpinhearing.co.uk
- Hearbase, Kent www.hearbase.com
- Hearing Healthcare Centre, Cambridge www.hearinghealthcarecentre.co.uk
- Correct Hearing, Nottingham www.correcthearing.co.uk
- Hearing Matters, Knutsford www.hearingmatters.co.uk
- Edinburgh Hearing Practice, Edinburgh www.edinburghhearingpractice.co.uk
- Invisible Hearing Clinic, Glasgow www.invizear.com
- Beacon Audiology, Dublin www.beaconaudiology.com

AB has also created links with retail partners to sell AB products and accessories online.* Their contact details are:

- Connevans www.connevans.co.uk
- The Ear Foundation www.earfoundation.org.uk/shop

AB will continually expand the AB certified retail partners program. Details of new retailers will be updated on AdvancedBionics.com.

For further information or to contact Advanced Bionics directly, please email info.uk@AdvancedBionics.com or visit AdvancedBionics.com

*Products and services available may vary between retailers and online services are only available for shipment in UK and Eire.

SoundSuccess™

Communicate with confidence

SoundSuccess is a unique online program developed for anyone wearing hearing aids, considering a cochlear implant, or who recently received a cochlear implant. The resource has been designed to help improve your patients' confidence in using hearing technology, ease of understanding different speakers and ease of listening in noisy environments.

SoundSuccess features a wide range of self-directed exercises for your patients to explore on their computer or tablet, anytime, anywhere.

If you would like further information on this important resource or would like to find out how you can access SoundSuccess, email Advanced Bionics at spp.uk@advancedbionics.com.

From Cochlear

Making a noise about cochlear implants

On International Cochlear Implant Day, Thursday, February 25, Cochlear Limited, together with hearing care partners and recipients around the world celebrated how this cochlear implant technology has changed the lives of over 400,000 people around the globe with severe to profound hearing loss. Around 10,000 people in the UK have a cochlear implant, including children who generally have two.

To support this international day of recognition, Cochlear shared inspiring stories on social media of people who are part of the global Cochlear Family and who describe their devices as "a gift", "a miracle" and "life changing". It was a privilege to share these stories of courage and celebrate the achievements of our implant recipients and their loved ones.

Here is one:

Miracles do happen!

"It is 12 and 14 years since I received my cochlear implants, opening a whole new world for me. I can communicate again, socialise again and live again. My biggest joy has been music, the one thing that all the technical equipment, vibrating alerts, flashing light and my beloved Hearing Dog (for sounds at night), could not compensate for.

As an opera buff I promised myself that, if ever by some miracle my hearing could be restored I would, no matter what the cost, go to Glyndebourne again and I have kept that promise. My radio in the car is always on, set to classic FM and my CD collection is growing. Having my CI's and my Hearing Dog too, who thinks I am a bit of a fraud, I have the best of both worlds – the deaf and the hearing. "



Liz Arendt, MBE and hearing dog Maple

If you would like to read more about personal experiences of Cochlear recipients or would like to speak to somebody with an implant, Cochlear can put you in touch with a volunteer. Visit www.iwanttohear.com

Nucleus® 6 is now available for all Nucleus users including the very first implanted over 30 years ago

With Nucleus® 6 you can enjoy substantially improved hearing performance and ease of use with SmartSound® iQ, Aqua+ and Wireless Accessories, all delivered in the smallest sound processor ever.

Why upgrade?

The Nucleus 6 Sound Processor is our most advanced hearing solution to date, designed with a clear purpose – to help you enjoy simply smarter hearing.

Simply designed for your needs

- Small, light and ergonomically designed for all day wearing comfort
- With its new water repellent coating, you can relax around water and be confident your system is protected
- Compatible with the new Aqua+ Accessory, which allows you to swim or dive

Smarter hearing made easy

- SmartSound iQ, automatically adapts to your environment for a better hearing experience
- Easily manage your sound processor with the remote assistant
- Stream music, TV or hands free phone calls directly to your sound processor

What Nucleus 6 upgrade users say:

- "I cannot even feel it on my ear!!"
- "Amazing that I was not disturbed at all by the noise at the restaurants"
- "I can hear really well on the phone!"
- "Music direct into my ear - how cool! "

To see how users of our first generation implant (N22) experience their upgrade to Nucleus 6 please visit www.cochlear.com/uk

From MED-EL

Want to join the band? Apply now for the MED-EL UK Music Grant!

If you secretly harbour a desire to play a musical instrument or improve your existing skills, and are a MED-EL implant user, your dream could be one step closer if you apply for the MED-EL UK Music Grant.

There are two categories of grant based on age: under 19; and 19 and over. The winners will each receive a musical instrument of their choice up to the value of £500, and one 30 minute lesson per week for a year. (All tuition fees will be paid directly to the music tutor). There is also a £30 allowance for sheet music.

So if you want to join our growing list of musical maestros and make music a part of your everyday life, make sure you submit your application before the deadline of 29th July 2016.

For more information, terms and conditions, and an online application form visit: www.medel.com/uk/info, alternatively please email conferences@medel.co.uk for a paper application form or call the marketing team on 01226 242874.

So make 2016 YOUR year and tell us why music is important to you on your Music Grant application form.

Good luck everyone!

Booked your holidays? Buy your WaterWear!

Now that Spring is finally just around the corner, like yourself, many MED-EL CI users will be planning their next holiday. So whether you are booking a break by the sea, an ocean cruise, or just plan to relax by the pool, remember to order the BTE WaterWear accessory or WaterWear for RONDO.

The WaterWear accessory is a transparent cover which is simply put over your audio processor and closed with a single-use, adhesive strip to provide a tight seal. The cover may be used up to three times and provides an inexpensive, fully waterproof solution for bathing and swimming, with no loss of sound quality.

If you wear a SONNET, or OPUS 2 processor please order the BTE WaterWear package. The WaterWear for BTE is designed to be used with the standard battery pack cover; if you use OPUS 2XS (2x batteries) please exchange your battery pack for the standard battery pack (3x batteries), to ensure a tight fit.

The WaterWear package contains three WaterWear covers with nine adhesive strips, and compatible batteries. (N.B. it is not possible to use regular Zinc-air batteries together with the WaterWear).

So if you want to make a splash on your next holiday, simply order the WaterWear package from the MED-EL UK Shop. To order email, orders@medel.co.uk

For more information about WaterWear, the RONDO, SONNET and other MED-EL products and accessories, visit www.medel.com/uk

Speech to Text Reporters in the UK

It is not always realised that as a user group NCIUA are often approached to respond to consultative documents on behalf of our members and CI users in general. One such document was the Market Review of British Sign Language and Communications Provision for People who are Deaf or Have a Hearing Loss from the Disabilities and Work Opportunities Division of the Department for Work and Pensions. Our response, largely written by Paul Tomlinson, makes interesting reading.

We pointed out that although CI users get huge benefit from their implants there were still situations – public meetings and similar events – where they needed communication support. As very few CI users are familiar with BSL this means they need a Speech-To-Text Reporter (STTR) who can give a verbatim report of what is being said or a Registered Note-taker who will provide a précis of the proceedings rather than a full transcript.

We provided some interesting facts about the huge lack of provision in this area. Although it is estimated that there are more than 900,000 people in the UK who are severely or profoundly deaf there are only 17 registered STTRs and most are based in London and the South East. The National Registers of Communication Professionals working with Deaf and Deafblind people only list 15 Registered Note-takers. The cost of employing communication support is also prohibitive with STTRs typically costing £250 or more per session.

We considered whether there were any technologies that might help to address the issue but it is difficult to see if they will make an impression in the near future. The geographical spread of support workers is a serious issue, and in principle the use of telephone based remote transcription services has some potential to address this issue. However our experience to date has been that whilst remote transcription can be of value in a one to one interview situation they struggle to cope with a multi-user environment.

One emerging technology which does offer some potential is that of real time speech recognition, as [for example] implemented on Android tablets and smartphones. When combined with a good quality internet connection these systems can give a very creditable interpretation of what is spoken into them. However they are currently only of help in the one to one conversation situation.

Most deaf people have never seen a STTR in operation and are unaware of their rights with regard to communication support. The known popularity of TV subtitling is one indication of the demand that could emerge in these areas if only deaf people would come forward and ask for what they need. Having said this I must admit that many years ago when I was approached to support a campaign for TV subtitling I backed away thinking the cost of doing this was insurmountable but I was proved wrong!

On a personal note

A few years ago I became a volunteer with the British Horse Society – horses and riding have been a lifelong passion - and now currently hold the post of Access and Bridleways Officer for Bucks which means I am the person to whom problems on bridleways are reported. I manage to attend the meetings of the local committee and follow up to a point with a little help but being able to participate in larger meetings is not possible unless I have support. Recently I became a member of the Bucks County Council Local Access Forum which brings together representatives of organisations involved with the rights of way such as the Ramblers and the Chiltern Society. I represent equestrians on this body which meets three times a year in the County Hall. I could not ask my long suffering husband to help me so I took courage in both hands and asked the County Council for a STTR. It is really wonderful being able to participate fully in this body and to make sure that they do not overlook the needs of horse riders. However, mindful of the expense of supporting me, I do try to be a very conscientious volunteer.

Alison Heath

A New Ambassador

NCIUA is pleased to announce the appointment of Deaf Olympics athlete Melanie Jewett as our official ambassador. Melanie won the bronze medal in the marathon at the 2013 Deaf Olympics and remains in training. Melanie has a cochlear implant and has benefitted enormously from this life transforming treatment for severe/profoundly deaf people. She has never let her deafness hold her back – she holds a responsible job in IBM and is fully engaged in the normal hearing world. Melanie will help us bring awareness and information to the outside world about the huge benefits of cochlear implantation and also provide encouragement for and advice to potential and new cochlear implant users.



Hearing Link

“
The Hearing Link Helpdesk was extremely easy to contact and gave lots of essential information & support over the phone.”
Shona Hudson, Helpdesk Engineer

We understand that hearing loss affects far more than your ability to hear.

Our Helpdesk can provide the information that suits your individual needs and those of your family & friends.

Email, call or SMS today with your questions:

Email: helpdesk@hearinglink.org
Tel: 0300 111 1113
SMS: 07526 123255

Hearing Link is a UK charity active in England, Scotland, Wales and Northern Ireland for people with hearing loss, their family and friends.
Board Office: 1114 The Princess Road,
Bangor, County Down, BT20 9JH. Scottish Charity No. SC107968

www.hearinglink.org  

Access to Work

There is a new guide to obtaining grants for practical support if you have a disability to help you:

- start working
- stay in work
- move into self employment or start a business

For deaf people this means that grants can be obtained for equipment to aid communication such as special telephone aids, communication support and so on.

The full guide gives detailed information on the various aspects of claiming this grant and also many useful links can be accessed by using the following link:

<https://www.gov.uk/access-to-work>

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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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