



*From left to right Sarah, Hilary, Esther, Jonathan, Rachel and Charlotte.*

## LET THERE BE MUSIC AND ...

The concluding event of the Summer Meeting & AGM (see page 3) was a musical workshop given by a quintet of musicians from the London Symphony Orchestra. Each player gave an insight into the structure of their instrument, its musical characteristics, how their instrument worked and then played a demonstration solo. The audience were able to feel the instruments while being played and discover the bodily sensations of musical sound waves. Sarah Quinn, violin, played Meditation by Massenet from the opera Thais. This is a haunting, beautiful melody which evoked a lot of audience reaction. One lady in the audience who had only been implanted 4 months ago said that "It is the first time I've heard it profoundly and was so moved that it made me weep". Esther Sheridan, clarinet, played the Cat extract from Peter & The Wolf by Prokofiev; it was very convincing! Jonathan Lipton, French horn, explained that although all brass instruments had keys and valves to vary the sound pitch, the actual creation of the music was governed by the player's lip formation and shape. He likened the tone of the horn to that of the human voice being so emotive. He played Moon River by Henry Mancini which proved his point. Hilary Jones, cello, and Charlotte Seale, harp, demonstrated the huge musical range and complexity of their instruments.

Introduced by Rachel Leach the group then played 'O Sole Mio', a traditional Italian song. This is better known as the theme tune for the famous Cornetto ice

cream advert of the 70's. Rachel took us through her own special arrangement and the players in turn showed how their part contributed to the whole. Hilary gave the underlying beat of the 'Habanera', a Cuban dance, which was very evocative. Rachel sang the words and the audience joined her in a rousing finale.

The London Symphony Orchestra (LSO) is widely regarded as one of the world's leading orchestras. Its many activities include an energetic and groundbreaking education and community programme (LSO Discovery), a record company (LSO Live) and exciting work in the field of information technology. Through workshops, projects and master-classes, LSO Discovery has become a world leader in taking music and players of the Orchestra into the community, and making the LSO relevant to the lives of thousands of people beyond the concert hall.

Rachel Leach is a composer and animateur. Rachel has written pieces, devised and led education projects for many of the UK's finest ensembles, orchestras and opera companies. Her music has been recorded by NMC and published by Faber. Writing for children and amateurs is a large part of Rachel's work. Her output includes dozens of pieces for LSO Discovery as well as many songs for children and training pieces for young musicians.

*(If you were at this musical performance, what did you experience? Please write or email me so that we can share that with those who were unable to be there - Ed)*

## LOOK AT ME

This was the title of a reception held by a UKCoD on 29 April 2009 at Westminster in advance of Deaf Awareness Week on 14 May. 'Look at Me' posters promoting Deaf Awareness Week emphasise the need for the public to



look at someone who is deaf or hard of hearing so that they can see the speaker's lips and facial expressions. Paul Tomlinson is our representative and a trustee of UKCoD which is an umbrella organisation, part funded by the Government, to support and promote the interests of all deaf and deafened people and the numerous organisations that exist on their behalf.

Susan Daniels, Chair, and CEO of NCDS, in welcoming all the delegates including many MPs, introduced Mr Bruce, Chairman of the All Parliamentary Group (APG) at Westminster and thanked him for his and the Group's work on behalf of the deaf. Mr Bruce stated that at the next APG meeting in May they would be drawing up a programme of activities for the remainder of this Parliament. Susan said that the vision of UKCoD is to assist the deaf to participate fully in society and this was reflected by the wide variety of organisations which comprise UKCoD and of the numerous delegates present.

Susan introduced Doreen Woodford of the Woodford Foundation who spoke passionately about the Foundation's work internationally to help deaf children receive an education. Born of deaf grandparents and parents and now aged 89, Doreen's work had begun in the UK but since 1980 she has been concerned primarily with the situation of deaf children in Africa and particularly Tanzania, Malawi, Somalia and Uganda to which she has travelled extensively.

Rodney Clarke, St Andrews Health Care which sponsored the reception, noted that in Malawi there are over 7000 deaf children who will never go to school or receive any help in their lives. This was typical of the poor and underprivileged deaf in Africa. He urged delegates to consider partnerships with his colleagues and extend their responsibilities to help others.

## INFORMATION DAY

The CICS Group held an information day on 15 March at the Arlington Arts Centre, Newbury which was attended by a large group of adults, the majority of whom were parents of deaf children who use cochlear implants. Introduced by the CICS Group's Chairman Tricia Kemp, who is also our NCIUA Vice Chairman, there were two principal speakers in the morning session and following a buffet lunch, delegates had the opportunity of choosing two out of seven workshop sessions before the final presentation of the day.

Melinda Nettleton reviewed the changes to the SEN Tribunal regulations which govern the issues of appropriate school placement, level of support within school and of additional input such as speech therapy, for all children who have special needs such as hearing impairment. Whilst we adults often have cause for complaint about our situation we should all consider ourselves fortunate that we do not have to face the arduous struggles of the parents of born deaf and deafened children as they plough their way through the laborious bureaucracy and indifference that is often encountered in getting support for their children.

David Canning spoke about transformational spaces and the modern concept in school design concerning the difficulties in hearing (!) people communicating in the difficult acoustic environments which are often found in schools. These issues are of even greater concern to hearing impaired children. David explained certain British standards (BB93) on acoustic environments in schools in respect of levels of noise, reverberation times and signal to noise ratio levels. There is now a Paediatric Audio Visual Test (PAVT) which can be conducted to assess the suitability of classrooms. He recommended that parents seek to assess the acoustic performance of schools where a school choice is involved.

David explained that 60% of children's communication in school is with other children and such levels of noise can create difficulty for both the hearing-impaired and normal hearing children. Group work in the classroom is now central to school learning and this presents additional problems to hearing impaired children.

The workshop sessions were: Top tips for Statementing; Developing higher listening and language skills; Are implanted teenagers different to their hearing peers?; The latest on bilaterals; Speaking out; The latest news from manufacturers; and Children's FM systems.

The afternoon closed with a presentation from Julie Mather on the way cochlear implantation has been transforming educational opportunities for deaf children. This encompassed a brief history of paediatric cochlear implantation in the U.K. and looked at the growing trend towards mainstream education.

## SUMMER MEETING & AGM

Nigel Williams, Chairman, opened the Association's Summer Meeting held on 6 June at The Royal Free Hospital, London and thanked everyone for traveling to this major event in the Association's calendar. In an action packed agenda he welcomed six speakers who made presentations to a large audience.

The main presentations were by Tony Murphy of Phonak on FM Systems (see page 4/5) and the keynote address by Mr Azhar Shaida from RNTNE on "Cochlear Implants-The Next 20 Years", which will be published in the Autumn edition.

For the manufacturers, Denise Cafarelli Dees from Cochlear spoke about rehabilitation, of their adult rehabilitation, of "Here we go"- a specific resource for teenagers and "Sound around" for interactive workshops. Kate King, advocacy specialist for Cochlear and mother of a 16 yr old implanted son, spoke about her role in raising the awareness of cochlear implants, of her work in helping charities and of the Graeme Clarke scholarship (see below).

James Mander, clinical specialist Advanced Bionics, spoke about their initiatives for 2009 including the audiology working group, the rehabilitation audiology group and partnering user support projects at CI Centres. They have increased their investment in rehabilitation such as Sounding Board, run by the Ear Foundation in Nottingham. James also reviewed a series of new product accessories.

Cassandra Brown, Managing Director MED-EL, spoke about their focus on music because as many as 50% of CI users are really disappointed in the quality of music which is important for lots of very emotional reasons. "Music produces the kind of pleasure that human beings cannot do without". Music has a wider dynamic and frequency range than speech. Cassandra contrasted the problems of music with all its fine detail structure to the relatively simple speech envelopes and demonstrated the comparisons.

In his Chairman's Report at the AGM, Nigel reviewed the events of the past year and highlighted the very positive recommendations of the NICE report despite the fact that bilateral implants for adults were not recommended. He said that we now need to ensure that the necessary research to prove the cost effectiveness of adult bilaterals is undertaken in time for the next NICE review in February 2011. All the reports submitted to the AGM were accepted and the current members of the Executive Committee (see page 8) were re-elected. Nigel thanked the Committee members for their hard work and support and he thanked the manufacturers Advanced Bionics, Cochlear and MED-EL for their continued sponsorship of our meetings.

## GRAEME CLARK SCHOLARSHIP AWARD

Cochlear UK is delighted to announce Amanprit Johal from Sutton Coldfield, Birmingham as their first UK winner of the international Cochlear Graeme Clark Scholarship Award. On presenting Amanprit with the award at a ceremony early in March this year, The Lord Mayor of Birmingham said "It's wonderful that programmes such as this are available to assist cochlear implant recipients in their further education, and that Amanprit is studying here at the University of Birmingham".

Amanprit, who is 22 years old and studying for a BSc in Geography and Urban and Regional Planning was chosen from a number of exceptional candidates. She said: "I'm over the moon and words can't describe what an honor it is to accept the scholarship. The award is above all an emotional support showing that all my efforts and continuous learning have been worth it". On hearing she had won the award, Amanprit plans to use the scholarship to complete an MSc in International Planning at University College London in September 2009.



The Cochlear Graeme Clark Scholarship Award provides college age students a grant for tuition, for students either currently completing their final year of school and who have been accepted onto a university or other tertiary education course or students currently undertaking a university degree of other tertiary education. For further information potential candidates for the 2010 award should email [kking@cochlear.com](mailto:kking@cochlear.com) or visit [www.cochlear.co.uk](http://www.cochlear.co.uk)

## FM SYSTEMS



*A summary of a presentation at the Summer Meeting 2009 by Tony Murphy of Phonak UK*

“I am going to talk to you about FM systems and some of the limitations of cochlear implants and give some

pointers in the direction of useful things that can help you in your lives to improve your hearing and understanding in different, difficult situations.

Whilst cochlear implant users are generally pleased with their outcomes all users are fully aware of some of the current limitations of this modern technology. One of these is the limited range of the microphone in the device and another is the problem of background noise which masks the incoming sound. The microphones have, on average, a range of about 2-3 metres depending on the acoustic environment and thus good speech perception drops off considerably as the sound source moves farther away. Directional microphones can only do so much. The issues of background noise are multiple and severely affect the signal to noise ratio (SNR) which needs to be maximised to achieve a satisfactory result

Clever electronics in the sound processor can now provide a wide dynamic range, though still less than normal hearing as the processor has to compress the incoming signal to achieve a satisfactory result. Noise cancellation and multiple programmes can provide specific solutions. Both frequency and temporal resolution are also compromised and this affects the perceived sound range and speech perception. The room we are in today has some acoustic problems and there isn't a hearing instrument in the world that can solve that. The problem is unless someone can invent a hearing instrument that knows what I am going to say before I say it, it doesn't matter how wonderful that technology is within the hearing instrument, if that information is missing before it goes into the device microphone there is very little one can do about it.

But there is a solution outside of the sound processor and this is wireless technology or as it generally known FM. The technique is to wirelessly connect the sound source directly into the sound processor thus by-passing the environment of the speaker and the listener and eliminating all the acoustic and noise issues mentioned above. The

speaker has a microphone and a FM transmitter and the listener has an FM receiver plugged directly into their processor. These processor plug in adaptors are very light weight and are self powered.

There are several situations where FM systems can be very effective for cochlear implant users (see Figure 1). In the home, the TV can have the transmitter plugged into the back of the TV and the CI user can enjoy the TV programme without affecting the room volume level for other viewers.

### FM offers proven benefits for CI recipients

- Improved signal-to-noise ratio
- Reduced effects of reverberation
- Better communication over distance
- Better use of small dynamic range
- Higher performance and understanding in real life environments
- More freedom of movement for speaker and listener

*Fig1*

In the car where there is always a lot of road and tyre noise, CI users can hear much better if their passenger(s) use the FM microphone. For mobile phone use, where 3G instruments are the best for CI users, the user can have a hand free set up which again improves the S/N ratio. Extending this feature can provide hands free mobile phone use in the car which can be very effective. Most pubs and restaurants are noisy places and again here the FM system setup can be very beneficial. And again at social functions, parties and other such gatherings a FM system will give valuable support and make the occasion more enjoyable. In all these scenarios the user can either use their own FM adaptor or use a neck loop with their T coil setting. Whilst all these situations will involve in part some cable linkups, these are minimal and well worth the effort.

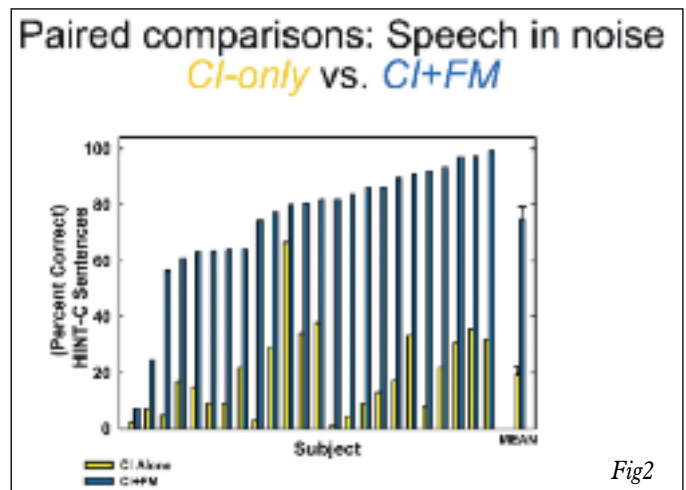
Bluetooth technology can also be brought into play which eliminates cable connections. This is very clever but it is important that both instruments are not only Bluetooth compatible but also that they are matched, that the components can ‘talk’ to one another. Price and thereby quality plays a part here. You know the adage –you only get what you pay for; well that is very true in this matter and professional advice is recommended in selecting the system components.

For those CI users at work, a FM system can be very important when faced with business meetings

and group discussions. This equally applies to students in lecture halls and school children in classrooms where the speaker is often some distance away and there can be a high level of noise.

The results of a study of 24 users looking at speech in different noisy type environments for various different cochlear implant wearers are shown in Fig 2. The yellow bars are the cochlear implant alone and the blue bars with FM. You can see that in most cases how much speech understanding has been dramatically improved by using FM system. The mean result of the study was a threefold improvement in speech recognition. If anyone has any doubts whether or not they would benefit from an FM systems, these results just goes to prove that.

Phonak offer several system levels. The starting point is EasyLink transmitter which can be used with the MyLink receiver. This setup is ideal for home or leisure use. ZoomLink enables the user to change microphone settings. The next level is the SmartLink transmitter. Then the Inspiro which has built in both a monitoring facility and SoundCheck which measures the sound/noise levels and adjusts itself to maximise performance.



We do not sell directly to members of the public but have a network of over 70 FM distribution centres across the UK (see [www.phonak.co.uk](http://www.phonak.co.uk)). Our products are also available from RNID (see [www.rnid.org.uk/shop](http://www.rnid.org.uk/shop)) and Connevans (see [www.connevans.co.uk](http://www.connevans.co.uk)) It is important that you understand your needs and get the system that you actually want. You can ring us up at any time, feel free. You can ring me directly, talk to me, ask questions, no issue at all. Advice is free!" (Tony can be contacted at 07766993468 or email at [Tony.Murphy@phonak.com](mailto:Tony.Murphy@phonak.com))

## THE TWILIGHT LECTURE

Given by David McAlpine, Director UCL Ear Institute, London, on 12 March 2009

### What the Brain Knows about Cochlear Implantation

"Cochlear implants are one of the most successful prosthetic devices to date enabling many profoundly deaf people to hear speech and attend to a range of environmental sounds. However, whilst their success over several decades in this regard is self evident, surprisingly little is known concerning the brain's response to implantation. This lack of knowledge can make it difficult to understand why some recipients perform well and others do not. Stimulation strategies in cochlear implantation generally try to introduce patterns of activity to the brain that are considered important in normal hearing. To date, this strategy has been driven from the perspective of cochlear psychophysics, with little regard as to whether this is optimal from the perspective of the central auditory nervous system. Arguably, other than as a repository for an implant, the cochlea is the least important structure in the outcome of a pre-lingually-deafened implant user. It is important to establish the evidence for what the brain is actually responding to in cochlear implantation.

The auditory nerve fibres (ANF) degrade with deafness and one of the limiting steps in the performance of an implant is the extent to which the remaining ANFs can provide the lower brain centres with sufficient input to perform their functions as normally as possible. This is, arguably, more relevant than the issue of cortical plasticity. It may be necessary to review the function and performance of the spiral ganglion neurons. It's not yet clear what the brain itself needs from by aural reception and this is a subject for continued research.

In the developing world of bilateral implantation, whilst each implant may be perfectly satisfactorily mapped in isolation, mismatches can occur between the two implants, and sensitivity to binaural cues, such as interaural time differences, requires very careful balancing of the implants. Current implant strategies remain bilateral rather than binaural, and understanding what the brain requires to achieve binaural processing will be critical. Unfortunately, different neural survival patterns can complicate this situation.

I contend that a "reverse-engineering" perspective on cochlear implantation must be adopted, one that suggests "neuron-oriented" stimulation strategies designed for maximum performance in listening tasks. Understanding how the brain responds to implantation, and adapting or modifying stimulation strategies accordingly, will potentially improve the capacity of future auditory implantable devices."

# COMMUNICATION IN THE INFORMATION AGE



This was the theme of a conference held by the RNID on the 25th of April, 2009 which featured a number of international speakers on the subjects of deafness and technology.

Mark Downs, Executive Director of Science and Enterprise RNID, stated that its objective was changing the world for deaf and hard of hearing people. This would be achieved by preventing hearing loss, improving aid to hearing devices and restoring natural hearing through drugs and other medical solutions. It is estimated that the cost to the UK economy of the 1 in 7 people who have a hearing impediment is a staggering £13.5 billion and yet less than 2% of the money spent on medical research in the UK is aimed at hearing loss solutions.

Mark reviewed the progress in the past ten years of the RNID's £6.5 million investment in research support and in particular Dr Falconer of UCL, London on bimodal stimulation in the combined use of cochlear implants and hearing aids and Dr Rivolta at the University of Sheffield on stem cell research. Mark stated that RNID intended to double the amount of investment in research over the next five years and build a consortium of researchers dedicated to discovering drugs to aid or eliminate hearing loss.

Guido Gybels, Director of Technology RNID, emphasised that communication technology is a central element of modern life and thus was particular important to people with a hearing impairment. On the subject of convergence Guido illustrated the huge changes over the past 15 years from a range of low technology data devices and communications systems

into the current and increasingly integrated single platform approach embracing multiple applications.

Artificial Intelligence is the missing link in many areas, in particular speech recognition, but automatic speech recognition has nevertheless matured enough to start delivering real benefits to people with hearing loss. The use of broadband voice codecs in the new 3G world of mobiles was of particular relevance to hard of hearing people. The future could be that a hearing aid or a cochlear implant would be a universal terminal with multiple access to different modes of input. The challenges of the future developments were not only educating the engineers for this future but also the need for political commitment to subsidise areas of activity on the basis of disability together with the need to ensure coordination for complete end to end integration of all the technologies that were being developed.

Mark Downs also drew attention to the need to increase and emphasise the education of GP's on the subject of those medicines that are used in treatment of the other conditions which in themselves can damage hearing and RNID would be returning to the subject in the future.

Marcel Bobeldijk, President of the European Federation of Hard of Hearing People (EFHOH) outlined the role of this organisation which has 27 EU members countries amongst which there are 81 million people with a hearing impairment. Marcel gave figures of the poor to bad TV subtitle situation which although in the UK (99%) was extremely good, some countries such as Germany (24%) and Spain (40%) illustrated the work still to be done by the authorities concerned. Marcel is a member of the European Disability Forum (EDF) and also of the WHO-Europe working group of hard of hearing people. EFHOH was holding its annual convention in London coincident with this conference.

Chiara Giovannini of ANEC (The European consumer voice in standardisation), spoke of their work in preventing hearing loss through loud noise exposure. Over 250 million portable audio devices have been sold in the past three years across Europe and the current international standard allows for these to be played at up to 125dB. Consumer device standards could not be imposed to limit absolute sound levels some of which are actually enjoyed. ANEC's approach is to develop standards on time exposure with suggested limits of 40 hours a week listening at 80dB level and 5 hours a week at 90dB. There is no question that excessive music levels at concerts and from iPods and other portable listening devices do pose a serious threat to the hearing health of the current and future generations and thus work on standardisation and limitation of sound levels in this area is to be welcomed.

## EURO-CIU SYMPOSIUM



*From left to right Christina Ryberg (Sweden), Mary Ogwo CIGS, Tricia Kemp CIGS, Anne-Charlotte Gyllenram (Sweden), Sari Hirvonen-Skarbo (Finland) Epp Muil (Estonia)*

The 7th international symposium of the European Association of Cochlear Implant User national associations was held in Zaragoza, Spain on 17 April, 2009. Hosted by AICE, the local Spanish CI association, delegates were given a tour of this ancient and historic city which, during its 2000 years of existence, has experienced the varying cultures of Romans, Moors, Jews and Christians.

The conference featured a live video conference call from Australia by Dr Graham Clark, the inventor of the multi electrode cochlear implant, in which he traced the history of the technology. Talking of the future Dr Clark said that solutions from stem cells were still a long way off and that the longevity of implants was assured as there had been no evidence of degeneration over the 30 years of their existence. He added that the prospects of an implantable cochlear implant would be dependent upon the perfection of sensors on the ear drum to accurately reproduce incoming auditory stimulation.

Leo De Raeve from Belgium spoke on the counselling of and support for adult implant users. The availability of adult rehabilitation was haphazard across Europe and whilst it was very important that such support be available it often depended on proactive use by the implantee. Leo urged that adult rehabilitation should embrace not just audio therapy but the use of the processor, training in repair and handling situations and how to adopt techniques to overcome environmental problems.

Sue Archbold, the Ear Foundation reviewed the progress on improving the educational opportunities for deaf children. There were other presentations from professionals in France, Spain and Holland. At the AGM held the next day, Alison Heath represented the NCIUA. Alison is an Advisor to the EURO-CIU Board and Editor of their newsletter. Next year's AGM will be held in Varese, Italy and the next symposium in 2011 will be in Innsbruck, Austria.

## ANOTHER MIRACLE IN THE UK!

In the last edition (No 41 Spring 2009) there was an article about an auditory brainstem implant (ABI) operation in USA. The ABI system consists of a receiver/stimulator that is implanted into the temporal bone, a speech processor worn on the body, and a microphone. The device is similar in concept to the cochlear implant, except that the electrode design and surgical placement are aimed at the cochlear nuclei deep in the brainstem. Patients who have had the auditory nerve severed are not candidates for hearing aids or cochlear implants.

Although the auditory brainstem implant does not restore normal hearing, combined with lip-reading, most patients can once again communicate easily with their family and friends.

Deborah Mawman, lead coordinator of the Manchester CI programme, has correctly pointed out that ABI surgery is available in the UK at Manchester and also in Cambridge and RNTNE in London and we're very pleased to note this correction.

## GROUP NEWS

### Home Counties

8 Sept 2009

Brookes Bros Wine Bar, Holborn, London  
Just come along, join in and catch up on the latest CI chat

28 Sept 2009

Coffee Morning,  
Enfield

For further information on these events please email [hccig@hotmail](mailto:hccig@hotmail)

### South Wales

11 July 2009

Annual BBQ  
Laleston Garden Club

For further information please email [doreengunning@dsl.pipex.com](mailto:doreengunning@dsl.pipex.com)

## ART & CULTURE IN THE NORTH WEST

Arts About Manchester

Green Fish Resource Centre,  
46-50 Oldham Street, Manchester, M4 1LE  
is the arts marketing agency for Greater Manchester and the North West. They have set up a calendar to list accessible events of possible interest to cochlear implant users across the North West (presently 95% Greater Manchester). The calendar shows captioned and subtitled Films, Theatre and other events, along with audio described events for Blind people and BSL interpreted events for BSL users. Have a look at [www.artslist.org.uk/accessible/calendar.aspx](http://www.artslist.org.uk/accessible/calendar.aspx)

This should be very useful for hearing impaired people who like to get out and about. They would like to know what viewers think about it. Please send your comments to Mickey Fellowes (a CI user) at [Mickey@aam.org.uk](mailto:Mickey@aam.org.uk)

## TALK BY TEXT

Whilst many of us CI users are able to use a telephone there are users who have to rely on text messages either from their mobile phones or through Typetalk using minicomms. There is now a new piece of software for computer users called TalkbyText. This application will turn any Internet ready Windows PC into a fully working text phone which is able to make and receive calls, print and save your own conversations and set up answerphone messages and be notified of missed calls.

It runs in the background of your normal applications and when a call comes in, it opens a window to alert you. This useful piece of software can either be downloaded from [www.ictrnid.org.uk/tbthe.html](http://www.ictrnid.org.uk/tbthe.html) or installed by a CD which can be sent to you.

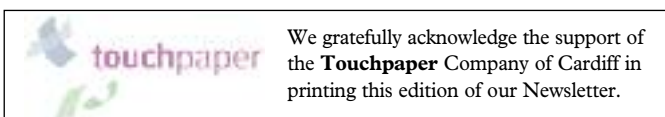
The long established and successful Typetalk service using minicomms now has a new name – **TextRelay**.

## National Cochlear Implant Users Association

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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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