

# The Emmeline Centre

## Newsletter

March 2011

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### Editorial

Hello again and welcome to the Spring 2011 Newsletter!

We would like to thank everyone who has contributed to this edition and hope you find it interesting and informative.

As usual things have been changing at the Emmeline Centre and you may have noticed some of the rooms now have even more fancy equipment in them. The Paediatric team can now do hearing tests in three rooms instead of just the one, which is a great help when booking all those appointments. We would like to thank the Cambridge Hearing Trust who so generously purchased both this new equipment and some new rehabilitation materials for adult patients.

The Adult team would like to remind you to return books and CDs when you have finished using them, then others can benefit as well.

We send our warmest congratulations to our Administrative Assistant, Lucia Haluskova (and partner Robert) on the birth of baby Samuel (Samko) in November 2010. We have enjoyed getting to know him when he pops in to see us. Eldre Beukes one of our audiologists is also off on maternity leave and we have two more babies on the way!

We are again hoping to send as many of the newsletters as possible out via email instead of posting a hard copy. If you would like us to add you to our email list for future editions please get in touch with one of us. You can send your email address to: [jill.bradley@addenbrookes.nhs.uk](mailto:jill.bradley@addenbrookes.nhs.uk) and we will send you an email consent form.

As usual we would ask anyone with old or broken spare processor parts at home to return them to Andy Taylor, our Technical Support Officer. You'll make his day!

**PLEASE KEEP ALL YOUR NEWS ROLLING IN.  
WE WANT TO HEAR HOW YOU'RE DOING AND WHAT YOU'RE DOING.**

**E-MAIL [susan.fields@addenbrookes.nhs.uk](mailto:susan.fields@addenbrookes.nhs.uk) OR [jill.bradley@addenbrookes.nhs.uk](mailto:jill.bradley@addenbrookes.nhs.uk)  
WITH ANY NEWS OR PHOTOS WHICH YOU THINK OTHER FAMILIES MIGHT BE INTERESTED IN.  
OR SEND THEM BY POST TO SUE or JILL AT THE EMMELINE CENTRE**

## STAFF UPDATE

# WELCOME

We warmly welcome to our team, Karen Ennew, clinic administrator, and Julia McHugh, administrative assistant. Julia is covering Lucia Haluskova's maternity leave.

We also said a temporary farewell with a baby shower to Eldre Beukes, who is off on maternity leave.



## SPOTLIGHT ON STAFF



**Frances Harris** : Lead Adult Rehabilitationist.

I qualified as a speech and language therapist in 1993. I have worked at the Emmeline Centre since 2005. I have a long standing interest in deafness and its impact on communication. There are three of us working on the adult rehabilitation team, and I have recently been appointed to manage the team.

What does a rehabilitationist do? On the assessment side, we see newly referred patients and consider how they use their hearing and communication skills. We combine our assessment findings with those from the medical and audiology teams. As for the follow up after an implant, we help a new cochlear implant user to listen for sound and speech and to use their equipment to the full.

Some of my work is also "behind the scenes". I aim to collect results across groups of patients, to show improvements after an implant. I am interested in how CI users hear music, how the CI impacts on tinnitus and how wearing a hearing aid can work with a cochlear implant. I also work with the rehab team to ensure our written leaflets are up to date and as clear as possible. Part of my new role will also be forward planning to make sure that the service continues to develop.

# **The Dominique Conte Foundation for the Deaf**

is looking for female models to be in our

## **Charity Fashion Show**

on Saturday 28th May 2011

**At Paradise Wildlife Park in Broxbourne**



Applicants should be 16 - 25 years of age, female, and be d/Deaf, and available for the whole of that day and a day beforehand for a rehearsal.

Applicants should contact Dominique on [12months12challenges@gmail.com](mailto:12months12challenges@gmail.com) in the first instance and for an application form.

Please see [www.12months12challenges.com](http://www.12months12challenges.com) for details about the Charity.

## **Auditory Brainstem Implants**

Frances Harris writes:-

*An auditory brainstem implant (ABI) is used much more rarely than a cochlear implant. At Addenbrooke's we have 12 ABI recipients. The experience of each is unique, depending on their particular type of surgery and their response to sound.*

*One of our ABI recipients was talking to us recently about his implant. This is his experience:*

### **Why were you offered an ABI rather than a CI?**

I had a tumour growing on my hearing nerve, and it couldn't be removed without removing the nerve itself. This meant having a cochlear implant was not an option, so I was offered the ABI.

### **Tell us about listening with the ABI**

When I was first fitted with the ABI, the sound I was getting just seemed like a humming sound. Every noise sounded exactly the same, whether it was a knock or someone talking, and if I'm honest I thought it was pointless, and I would be able to cope just as well without it.

It's now been just 11 months since my operation and I am amazed how things have changed. I can now tell the difference between different sounds. It's like learning to hear again and allowing your brain to adjust to the different sounds.

Before my operation I made my friends aware that I would need to use the ABI afterwards to be able to hear anything, and to begin with I think they were a little unsure how to approach me, but within just 30 minutes of them first seeing me one turned to me and said "So is your hearing ok then?"

They were amazed as to how well I could cope. Now they just speak to me as they did before. I do still need to lip read and occasionally my friends will forget and say something with their back turned or even ask me a question about the latest music!

### **In what ways does the ABI help you?**

The ABI to me now is very important. When I'm out it helps me to hear essential things like traffic and I become a lot more aware of my surroundings. At home I am able to hear the door bell and other essential things like the fire alarm; without it I would be oblivious to all this. It is much easier to talk to people with it on; lip reading becomes easier, and there have even been times when someone has asked me a question and I have not been looking at them and I have been able to understand. I am still learning and my brain is still adjusting so hopefully in time there will still be improvement.

### **What listening challenges do you still face?**

I don't wear my ABI all day as I do find I get tired as the day goes on. A lot of the time when I'm at home alone it's nice to take it off and just have a break. Everything with the ABI isn't plain sailing though. I still find it difficult to talk to certain types of people; for example, I find it hard work to talk to anyone with a large moustache, and people with heavy accents can also be a challenge. It was only recently I visited family up North and I struggled when a family member said the word "Car". To me it sounded like the word "Care" but after I asked them to repeat it the sentence made sense.

### **What do your friends and family say about it?**

My friends and family have been really supportive and they are all amazed at how well it works, and how over time things have improved. They all admit that to begin with it was a worry as to how I would be, and if it would be easy to hold a conversation with me. This was a big worry for me also, but everyone was pleasantly surprised. Now they don't think twice about approaching me.

### **What would you say to someone considering having an ABI?**

If anyone found themselves in the situation where they have been offered the ABI, the first thing I would say is not to worry too much when it is first being switched on. I imagine that like me you will hear just a humming sound and every noise will just be the same tone. Bear with it and before long you will be able to distinguish different sounds, and soon you won't be able to live without it. The brain is an amazing thing!

**This useful piece of information appeared in the BT Connections Newsletter for Healthcare Professionals (Nov 2010)**

**Emergency SMS for deaf, hard of hearing and speech-impaired people**

The Emergency SMS service has been up-and-running for just over a year. During this time thousands of people have registered with the service which lets deaf, hard of hearing and speech-impaired people in the UK send an SMS text message to the 999 emergency service. And it's proved to be a real life-saver. Over the last year emergency SMS has handled more than 300 real emergency calls - everything from reporting crimes that have led to arrests, to the birth of two babies.

However, before anyone can use the service they must register their phone first. It's easy to do and once that's done, should an emergency arise, all you need to do is send an SMS message to 999 and the police, fire, ambulance or coastguard will be able to respond. For more information visit <http://www.emergencysms.org.uk/>

**Dave Barrett**

Senior Inclusion and Accessibility Manager, BT Retail

**Help!**

**My speech processor isn't working!**

**What can you try?**

- Change the battery
- Switch the processor off then on again
- Check all the connections
- Change your T-mic (if you use one)
- Change the headpiece
- Is your microphone dirty?
- Is a light flashing?
- Put in drying case with a drying tablet overnight

Remember if you use a Med-El device (Opus 2) and we send you a new processor, you will need to pair it with your fine tuner.

***Still a problem? Contact the Emmeline Centre.***

## Ten websites of the year from Sounding Board!

<http://soundingboard.earfoundation.org.uk/>

1. **The Listening Room** from Advanced Bionics (<http://www.bionicear-europe.com>)
2. **Deaf Children Learning** gives lots of ideas and resources for teaching deaf children literacy (<http://www.education.ox.ac.uk/ndcs>)
3. **Starfall** is a great website for children learning to read with lots of colourful activities to teach and reinforce phonic skills ([www.starfall.com](http://www.starfall.com))
4. **Vocabulary.co.il** has loads and loads of games to make learning vocabulary fun including idioms, synonyms, analogies..... (<http://www.vocabulary.co.il>)
5. **Storybird** enables you to create your own story books using images provided on the site covering a variety of themes ([storybird.com](http://www.storybird.com))
6. **The Configurator** from Phonak gives you tailor made information about linking Phonak FM systems to all hearing aids and Cochlear implants (go to [Phonak.com](http://www.phonak.com) and search for FM Configurator))
7. **Voki** is a free service allowing you to create your own personalized speaking avatars to stimulate conversation and writing ([www.voki.com](http://www.voki.com))
8. **MCHAS** from the University of Manchester has lots of information relating to audiology and it's all in one place (<http://www.psych-sci.manchester.ac.uk/mchas>)
9. **Thinkuknow** has great materials about safety on line aimed at different age groups with subtitles and signing. ([www.thinkuknow.co.uk](http://www.thinkuknow.co.uk))
10. **Toondoo** enables you to create your own cartoons and add captions.... very motivating for youngsters of all ages ([www.toondoo.com](http://www.toondoo.com))

We find these rules helpful for teenagers going online:

### Top Tips for the Internet

(with thanks to **The Buzz** – see below)

Don't tell anyone your home address, your school or your mobile phone number

Remember that the person you're talking to might only be pretending to be a friend.

Don't meet someone you have made friends with online.

Make your password hard to guess.

Use a mixture of letters and numbers.

If you ever get a nasty email or see bad or abusive language, tell someone but do not reply to the message.

<http://ndcsbuzz.org.uk/>

## **Here is some information on some of our other hearing implant equipment**

### **New bone-anchored hearing aids (BAHAs)**

The Emmeline Centre is pleased to be offering new BAHAs from two companies, Cochlear and Oticon Medical, which offer more sophisticated digital technology than before. They are called the BP100 and the Ponto Pro. Around 35 of our BAHA users have tried them already and the results have been good.



We will be contacting eligible BAHA users for an upgrade to a newer device if they have had their existing device for more than 3 years, and if their hearing is suitable. We look forward to the release of a more powerful device from both companies over the next two years which should allow almost all BAHA users to benefit from the most up-to-date technology.

### **Middle Ear Implants**

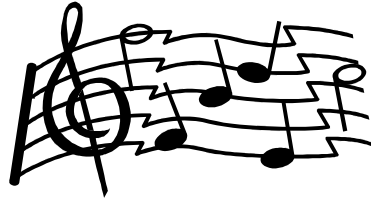
The Emmeline Centre is now offering middle ear implants, a new device for us which allows direct movement of the small bones in the middle ear. The device we are able to offer is made by Med-el, who also make one type of cochlear implant we also provide.

This device is suitable for people with a mild-severe hearing loss, who cannot wear conventional hearing aids but who do not suffer with ear infections.

The first three patients have undergone surgery and are doing well. We hope that once the good news spreads we will be seeing many more people for this new hearing implant!



# MUSIC WORKSHOP



What happens when you put 17 cochlear implant users (and relatives), two visiting speakers and three Emmeline Centre staff together in a room with a large TV and lots of music videos?? It was a lot of fun! An engaging music workshop took place on 17 September 2010, at Westminster College, Cambridge.

The day was sponsored by Medel, one of the leading cochlear implant manufacturers. Their consultant Geoff Plant facilitated the workshop. Geoff has around forty years' experience of hearing rehabilitation. He is also a keen musician; his ukulele was in evidence!

Medel has already collaborated with two young Scottish composers to commission musical works which could be accessible to cochlear implant listeners. One of these composers, Zack Moir, joined us for the workshop, playing his saxophone and talking about his composition 'Deacon'. This uses a careful choice of instruments, deliberate use of repetition (refrains and motifs), rhythm, alongside a narrative to guide the listener.

Geoff's style was to introduce his essential approach to music with a CI, and then use one example after another of music to evoke different reactions. His approach would be:

- Listen to music which is acoustically less complex at first
- Listen and watch at the same time
- Choose music with a strong rhythmic element
- Begin with familiar music; be prepared to try new styles too
- Listen listen listen!! Keep listening to develop skills.

Less complex music is likely to be smaller groupings of instruments, (small group rather than orchestra). Also the sound is easier to follow if the instruments are well separated in terms of register [pitch] and have distinct sound qualities [timbre].

*continued*

## MUSIC WORKSHOP *continued*

Watching performers, on DVD, online or live, is also likely to give better appreciation of the sound and the origin of each type of sound. Geoff kept emphasising how important it is to keep going with music; keeping listening again and again to develop your listening preferences and your skills in selecting musical features.

The range of music was wide: including John Denver, Bjork, Rod Stewart, unusual oriental string bands, the Peace Project, Johnny Cash, as well as the world's two best known tunes: Auld Lang Syne and Happy Birthday. All of the CI users present reported that they had seen more possibilities for discovering music for themselves. 'More of the same please', was their verdict! We were all very grateful to Med-el for the hospitality offered: the venue was very pleasant, with a delicious complementary lunch included.

Back at the Emmeline Centre we have developed more resources for introducing music to our implant users. The rehab team would be happy to see you for an additional rehab session if you would like some fresh guidance on listening to music. (You don't have to be new to your CI to have a rehab session!) We also have more stock from Medel of their complementary DVDs, which we are happy to loan out for the short term. We look forward to seeing you soon!



Frances Harris  
Adult Rehabilitation Team, October 2010

### **If at first you don't succeed.....**

I apparently screamed my way through the first three years of my life, with ear abscesses. The next six years were spent moving around about London to avoid the bombs, so I cannot imagine what my medical records looked like. We moved to Cambridge in 1945 and having my tonsils out at Addenbrooke's changed all that, as did the introduction of penicillin.

With perforations in both ear drums I was prescribed a body worn hearing aid which I absolutely refused to wear! But by this action unconsciously I became a good lip reader. I remember feeling totally stupid when playing netball, and not being able to hear the games mistress through the noise in my head, and wondering why – and then working out it was because I was so hot that my blood was rushing through my head, hence the noise. This would have been about 1946 before the British Tinnitus Association started.

I think I was about the sixth person in Cambridge to receive the behind the ear BE11 when they were introduced by the NHS in the early seventies and it made me realise how much I had been missing. However I chose secretarial work (!) and attended the Technical College, only using a hearing aid with a head band in the last year. I moved from one job when the stress became too much to bear with heightened tinnitus, and from another when a lovely man with a delightful French accent became my new boss and the strain of understanding him became too much.

The first time I mentioned the tinnitus to my GP was in my 30s; both my daughters had had chicken pox, then measles, then mumps, one after the other and I wondered why I could not cope with the tinnitus. This was the early 70's and a Tinnitus Group had been formed in Cambridge, so I joined it to learn so much more about how to help myself.

I am very lucky to have a happy disposition, enjoy music and singing so much, and in fact, very early on had had ambitions to use my voice in some way and now regret lacking the courage to follow this up.

I had worked my way up through the various strengths of NHS hearing aids, and was able to have just one month's trial of the then "new" digital hearing aids in late 2005/early 2006 when my hearing failed totally. We self funded my Med-El cochlear implant (I was 35<sup>th</sup> in the queue for an NHS implant, and they were only doing 2/3 a year then); I was switched-on on 20th December 2006. (I remember my first reaction was to be so grateful that the new sound masked the tinnitus).

Those first few months were magic; the birds' songs changed from 'squidgy' sounds to pure tone songs; dog walks with my husband were great fun, with John repeating many difficult phrases until I got them right; I read right through Jane Austen with audio books (and this, I strongly believe was the greatest help of all); I listened to simple songs and much loved music. I accepted my own voice knowing that as time passed and the brain learned to accept and understand all the new sounds I would experience great improvements in my hearing in every way.

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*Continued*

I will always be amazed at the technology, will always be so grateful that this happened in my lifetime and that we in Cambridge have the experts with the skills to make so much difference, in my case, Mr. Roger Gray.

I first started questioning my own voice at the beginning of 2010 – three years after being implanted; I was assured by everyone that it sounded just the same to them. It became increasingly strained, to me; after meetings I was much more tense than usual, experienced stress headaches all over again, and had a sore throat through the effort I felt I had to make to get myself over to the (mainly hard of hearing) audiences I was addressing. I requested an appointment for retuning, but how do you explain something that just doesn't exist for the audiologist in front of you? I fully realise that implantees' voices will always sound "recorded" to the implantee, due to the method of receiving the sound via the implanted electrodes, but this was different and distressing to me. I requested another appointment, some months later and Mark Chung was very patient and understanding and told me to go away and give myself the chance to adapt to the second, new tuning and to request another appointment if I was not happy.

I have written this article to encourage other implantees not to give up!

I can now hear my own voice in a much more natural way and don't feel the need to speak up so that other people can hear me! I quite expect to have to be retuned again, fully understanding that as time goes on our perception changes.

Avril Dring

#### **DID YOU KNOW ????**

**The Cambridge Hearing Trust** is a charity which exists primarily to support the work of the Emmeline Centre. Since its formation in 1988 the charity has spent over £900,000 in this way, including, most recently, over £79,000 to purchase additional audiological equipment which is now in use in the clinics and is referred to in the editorial on page 1. It also finances the production of this newsletter.

Further information on the work of the charity and how you can support it may be obtained from the Treasurer:

Ian Neville,  
30 Blythwood Gardens,  
Stansted,  
Essex, CM24 8HQ  
E mail: [i.neville@talktalk.net](mailto:i.neville@talktalk.net)

*This is your Implant Team*

**Surgeons**

Mr Roger Gray  
Mr Patrick Axon  
Mr Neil Donnelly

**Paediatric Anaesthetists**

Dr David Sapsford  
Dr Martin Herrick

**Clinical Lead: Hearing Implants**

John Briggs

**Clinical Lead: Adult Hearing Implants**

Zebunnisa Vanat

**Administration and Clinic Co-ordinator**

Marjan Adlington

**Medical Secretary**

Anne Parry-Smith

**Appointments Co-ordinator**

Ewa Rix

**Administrative Assistant**

Lucia Haluskova  
(Maternity Leave)  
Julia McHugh (cover)  
Karen Ennew

**Clinic Administrator**

**Equipment Officer**

Andy Taylor

**Specialist Nurse**

Cay Jackson

**Audiological Scientists**

Nicola Hatton  
Joanne Muff  
Abi Asher  
Louise Buttfeld  
Mark Chung  
Eldre Beukes (maternity leave)

**Medical Physicist**

Yu Chuen Tam

**Children's Team**

**Speech/Language Therapists**

Lesley Shipgood  
Carol Johnson  
Janet McKenzie

**Paediatric Rehabilitationists / Teachers of the Deaf**

Jill Bradley  
Kathleen Hamilton

**Adult Team**

**Hearing Rehabilitationists/ Speech & Language Therapists**

Frances Harris  
Sue Fields  
Becky Frewin

**THE EMMELINE CENTRE OPENING TIMES AND REPAIRS**

**There is always someone in the department from: 8.00am until 5.00pm Monday to Thursday and 8.00am until 4.00 pm on Friday, although there may be busy periods when the answer phone is on. Out of office hours the answer machine is on,**

If you require equipment or have a "break-down" and cannot get through, please leave a message on the answering machine and we will get back to you. Please do not just turn up, as there may not be anyone available to help immediately.

**Phone** 01223 217589 (voice )

**Appointments Line** 01223 348973

**SMS Text** 01223 410229 NB Calls cannot be transferred from this number

**Fax** 01223 586735

**E-Mail** [emmelinecentrereception@addenbrookes.nhs.uk](mailto:emmelinecentrereception@addenbrookes.nhs.uk)