

Newsletter

Issue 30 | Summer 2012 | South of England Cochlear Implant Centre

SOECIC 21st Birthday Party

We are delighted that so many patients and their families were able to come out on a cold January day to celebrate 21 years of cochlear implantation at the South of England Cochlear Implant Centre (SOECIC) at the University of Southampton.

It was lovely to see quite a number of adult cochlear implant users at the event as well as children and their families. Some people had only just received their cochlear implants whereas others have been using their implants for some years. The children enjoyed the various craft activities such as drawing pictures for the 21 poster. There were competitions for all ages and some beautifully painted faces.

Julie Brinton, joint head of SOECIC, welcomed everyone including our very special guests Mrs Rosa Cornhill and her husband Terry. Rosa was the very first patient to have a cochlear implant at SOECIC and cut the beautiful, celebratory 21 cake.



Sound is important to all of us, including cochlear implant users, so we invited Dr Steve Dorney, teaching fellow, from the Institute of Sound and Vibration Research (ISVR) to give us a demonstration of sound and how it impacts on our lives. This interactive demonstration was enjoyed by all ages. There were enthusiastic volunteers to answer questions and help demonstrate how a variety of different

strange shaped objects make weird and wonderful sounds. Okay, some of the sounds were not so tuneful! There was even a bowl full of water 'jumping' with sound. Everyone was able to go up and have fun playing with all the sound making objects during the party. Some of the children were especially keen to experiment with all the noise makers.

At lunch time we were entertained by Steve Charrett, a magician and everyone could have a piece of the delicious 21 cake with their lunch. We hope you enjoyed the chance to meet other cochlear implant users and their families and maybe renew friendships made in the SOECIC waiting room.

At the end of the party about 40 of the guests followed Steve Dorney and some blue '21' balloons over to the acoustic laboratories, which are in the building next door to SOECIC, for a tour. We were able to see and experience the wonky reverberant room where sound bounces off hard surfaces and simulates difficult listening conditions like a noisy restaurant with lots of hard surfaces. Also we went into the two anechoic chambers which are lined with special foam to deaden sound making them spookily quiet. Steve talked us through the research that these laboratories are used for and was impressed by the interest and questions from the group.

Well done to our competition winners who were:

21 quiz - Neil Whiting and Abigail Simpson

Sweets in a jar - Jacob Grasmeder

Name the teddy – Stacey Dart. The teddy's name was Norman



Patient Forum

Hello from David Cotter

I was first diagnosed as having a hearing problem when I was around 11 years old but this was not a serious issue until my early 20's when I lost the use of the telephone. My hearing loss continued to decline.



Last Spring Dr Jayarajan at RSCH suggested that I might be eligible for a cochlear implant. At this time there was a re organisation at work and I went through a period of uncertainty so all thoughts of the implant were pushed back. The day I knew my position was finally secure my wife Sandrine and I went out to celebrate at a restaurant. After the meal we bumped into Jo Deacon (who you may know from the Egham to Southampton bike ride) whom I recognised as a fellow hearing aid user. She told us how much she loved her implant and how wonderful her experience had been. It was such a coincidence meeting her then. I owe her a debt of gratitude for talking to me that day.

To cut a long story short I contacted Dr Jayarajan the next day and started the events that culminated in my having a Neurelec binaural implant fitted. I was truly impressed by the team at SOECIC - how patient and professional they were. I should also note that during this period I was fortunate to have the support from work to attend the appointments as needed. During all this I changed from being concerned about having the operation to being scared it would not happen!

On 17th Jan 2012 I had the operation and Mr Hellier and the other staff

were marvellous. Sandrine nicknamed me Princess Leia! (I bear no resemblance to her but the bandages around the ears and stuck out to give the impression of her hair style). On the third day the bandages were removed and all likeness to characters in Star Wars disappeared and I returned home to await the switch on.

I was switched on by Dr Cullington on 26th February and this moment I will remember for as long as I live. It was like my brain was a car engine starting to fire after a repair – it chugged a bit and eventually started to work. That morning I was able to distinguish between two different words just on the basis of the sound – the joyful thing was for the first time in years I was trying to listen to words and not trying to “see it” as if I ever previously struggled to understand I would look harder to try and lip read.

Since then I have been back to Southampton on several occasions for retuning and rehabilitation. My hearing has improved so much over this period – weird sounds have become normal, I became aware of my voice and now speak in a more relaxed tone. I am able to listen to music again and this has been such a pleasure.

I am now starting to use the telephone again on a limited basis. I have been able to order some garden tools over the phone and hold simple conversations with my wife for over 15 minutes – I could never comprehend all this before and my progress is exceeding my expectations.

I must admit all has gone well for me so far and I realise that everyone has different results. I wanted to share my experience with people. I am now able to do so much more in the space of a few months.

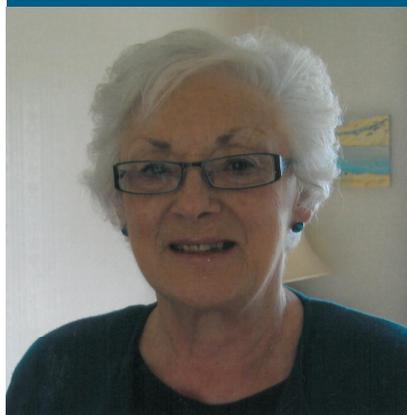
Not every day is the same and patience is required but the joy I feel for example when I listen to music is truly humbling.

Music in my life

I have only had my implant a short while - switch on was 8th June 2011 but already my life has improved so much.

Music has always played a big part in my life but as my hearing deteriorated my enjoyment was much curtailed. However on Monday 19th December my husband and I went to a Christmas Concert in St. Martins in the Fields and this time I could even join in the singing besides hearing all the words sung by the choir.

This is on top of finding socialising SO much easier, and enjoying large crowds to feed in my home makes it easier for my friends too.



I thought you might just like to hear my positive side - best wishes
Marion Evans

Update from Jo

A big thank you to Jo Deacon and friends for £800 raised from sponsorship. Jo presented this to SOECIC at the 21st birthday party in January.

Save the date

September 8th 2012

You are all invited to join us for a summer gathering at Royal Victoria Country Park. We look forward to seeing many of you and your families.

If you have any suggestions or comments for future social events please let us know.

A life changing experience

Soon after I completed my nurse training in 1968 it became noticeable that I was finding it difficult to hear. After tests I was given a hearing aid for my right ear. As time went on my hearing progressively decreased and I was given bi-lateral hearing aids. Working on busy wards became more difficult till eventually I retired from nursing six years earlier than I had intended. At that time I felt I was suffering a double bereavement, not only had I lost my hearing but also my life long career. I took a part time job caring for adults with mild learning difficulties, not quite the same as nursing but still in the caring profession. My family is rapidly increasing and I enjoy having my grandchildren around me. From an early age Lara my eldest grandchild now age seven loved singing and would often sing for me. One day after singing my favourite song Ava Maria Lara told me she wished my hearing was better. I wished that also but hearing that from Lara made me think seriously. I so wanted to be able to hear Lara's beautiful voice.

Within a short space of time I was referred to the South of England Cochlear Implant Centre at Southampton and was assessed for

suitability for implant. I was admitted to Southampton General Hospital on February 10th 2012 and the operation took place the same day. Post operatively I recovered well and was discharged on day three.



Switch on of implant was five and a half weeks later when the wound had healed and swelling reduced. Switch on is a really exciting time, rather like waiting for exam results. There is no guarantee that the implant will be successful. As I sat wired up to a computer and programming began there was no sound. Eventually after what seemed ages I heard sound like a bird twittering progressing to other sounds. The hearing process is slow because the brain has to learn to interpret the sounds. Several visits later and after more programming and speech and language therapy I am delighted with the results. It is still early days but my hearing should continue to improve. It will never be normal hearing. The sound coming from implant is bionic and takes

much getting used to. I will always have to wear my left sided hearing aid and will have to lip read. There is no upper age limit so those of you who read this who are struggling with hearing and finding hearing aids of little use do consider an implant. The cause of my deafness is unknown. It is probably genetic as our son Matthew is also deaf. He is managing well with hearing aids at the moment. I hope I will be a good role model for him should he need an implant in the future.



Grateful thanks to my beloved granddaughter for all the encouragement she gave me and to the wonderful team at Southampton Cochlear Implant Centre.

Alyson Buckle June 2012

Ode to my processors

Your magnet attracts my heart and that connection never comes apart.

Your red flashing light is like my heart pumping.

You are so red it's like you are blushing when you look at me.

Oh processors without you I wouldn't be able to hear and my life wouldn't be complete.

James Simms (aged 10 years)



World Deaf Chess Championships

Lewis Martin, aged 20, from Swindon will be competing in the 15th ICSC World Individual Championship to be held in Almaty, Kazakhstan from 27 September - 7 October 2012.

In December 2011 Lewis took part in a qualifying tournament which he won

to become the youngest player to represent England at the World Deaf Chess Championships. Lewis is currently the English Deaf Chess Champion as he has won the annual Championships for the last three years in a row.

He is currently a student at the University of Bristol studying Engineering Mathematics where he is President of the University Chess Club.



Forthcoming events

C4CI Grand Finale Concert

An exciting, visual and interactive concert of new works specifically aimed at cochlear implant users is taking place at the University of Southampton in September.



Dr Ben Oliver, the composer on the 'Compositions for Cochlear Implantees' (C4CI) research project, is currently composing new music for an ensemble of professional and outstanding student musicians to perform at the legendary Turner Sims Concert Hall. Project leaders Dr Rachel van Besouw and Professor David Nicholls will introduce the C4CI research project with a short public seminar about cochlear implants and music before the concert. Tickets are free and the best seating will be reserved on the day for cochlear implant recipients, hearing aid users and their families. The seminar and performance will be supported by a speech-to-text reporter.

When: Saturday 29th September, 2012 at 1pm

Where: Turner Sims Concert Hall, University of Southampton

Free tickets are available from the Turner Sims box office:

Website: www.tinyurl.com/C4CIGrandFinale

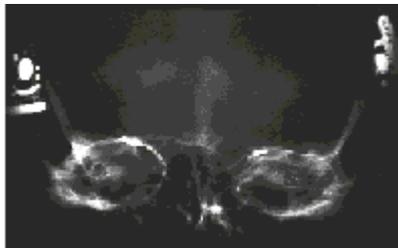
Phone: 02380 595151

For further information about the C4CI research project, please visit: www.soton.ac.uk/mfg/current_projects/compositions

Bilateral Conference

Parents of implanted children, adults with cochlear implants and any other interested parties are welcome to attend a one day conference on bilateral cochlear implants in children. This is organised by SOECIC and will be held on 11th April 2013.

As some of you may be aware, cochlear implants have been available in the UK for over 20 years. In 2009, a report by the National Institute for Health and Clinical Excellence (NICE) recommended that children receive bilateral cochlear implants. Fifteen UK cochlear implant centres formed a consortium to evaluate the safety and multi-disciplinary outcomes for these children. The papers to be presented at this conference will report the exciting findings from around 900 children. Results indicate that bilateral implantation for severely to profoundly deaf children is safe and helps them to achieve maximum benefit.



X ray showing patient with 2 implants

Conference Details:

Bilateral Cochlear Implants in Children: Safe and Effective

11 April 2013, Time: 09.30 to 16.00

Turner Simms, Highfield Campus, University of Southampton, SO17 1BJ

Tea / coffee and lunch provided

There is no charge if you are an implant user or the parent of an implant user.

Register at: <http://store.southampton.ac.uk/browse/product.asp?catid=48&modid=2&compid=1>
Email bilateralci@soton.ac.uk to ask any questions or register.

Teenagers, Telephones and Technology Try IT and Test IT Day

Saturday 20th October 2012

Are you aged 13 to 19? Would you like to get more from using the phone or, maybe try using one for the first time? Would you like to try out different phones to see which one sounds best? Are you interested in other technical equipment such as iPads, Bluetooth and Skype?

If the answer is yes to some (or all) of these questions, and you can understand some speech without seeing the speaker's face, then we have just the thing for you!



We are having a 'Telephones and Technology Try IT and Test IT day' for a limited number of teenagers in October. The day will include practical advice on how to use the phone and each teenager can have a 1:1 session with Debbie Hallmann, a hearing therapist who specialises in telephone training, to try out the new techniques with various phones including several mobile and landline phones. There will also be a practical session to try out different technologies e.g. iPads, Skype, Kindles and Bluetooth. Pizza and salad will be provided for lunch. We're sure the day will be an informative session mixed with a lot of fun and the opportunity to catch up with other teenage implant users. Places are FREE and will be offered on a first come first served basis.

Please contact Rebecca Ricaud, Teenage Co-ordinator rag@isvr.soton.ac.uk if you would like to come along and join us for the day.

Technology Update

Neptune wearing options

Cordelia Parke-Robinson's mother has come up with a clever way for Cordelia to wear her Neptune processors. She used iron on Velcro on the back of her processor pouches to attach the processors to iron on Velcro on the back of her vest. The Velcro holds the processors on well without the need for a harness.



rechargeable system. It is not compatible with accessories such as radio aids or personal audio cables so it would not be suitable for all situations.



SOECIC will not be providing them as standard but they may be purchased privately. Call the MED-EL office on 01226 242874 or email enquiries to orders@medel.co.uk. The current cost is £135 each.

Mini Battery Pack for Opus 2 processors

The mini battery pack is a new body worn option which can use a rechargeable DaCapo battery or an AAA battery. It can be used to connect assistive listening devices. It may be particularly useful for young children using radio aids as there would be less weight on the ear as the FM lead would be plugged into the Mini Battery Pack worn on the body rather than being directly connected into the Opus 2 FM battery pack cover. This option is available for new patients and for existing patients for whom it is appropriate.

Windshield for Advanced Bionics T-mic

One of our patients has found a brilliant solution to the wind noise being picked up by her T-mic on her Harmony speech processor. The microphone wind shields can be found on the following link:

<http://www.amazon.co.uk/Lavalier-black-Sennheiser-Audio-Technica-Countryman/dp/Boo4TGOUCK>



New equipment from MED-EL

Opus 2XS battery pack

MED-EL has brought out a new smaller battery compartment for the Opus 2 speech processor. It takes 2 batteries and is therefore both smaller and lighter than the Standard 3 battery pack or the DaCapo



You can now email Repairs direct:

soecic.repairs@soton.ac.uk

Reminders:

Adult CI users!

You may receive a questionnaire as part of your longterm follow up. Please complete this and return to us promptly, to help us to provide the best care to you. But remember that you can contact us **at any time** if there is anything you need or are worried about.

Help us to help the NHS :

Please look after your cochlear implant system. Did you know that your sound processor costs as much as a small car, your battery pack costs as much as a lap-top computer and your headpiece costs as much as an iPod? Each repair costs as much as a digital camera.

www.imallears.org



This is a website for teenagers who have a cochlear implant to chat to other young cochlear implant users, make new friends and have fun! It is part of a research study at the University of Southampton. By joining our site you will become part of this research team by helping us to build a picture of what life is like as a teenager with a cochlear implant. This is your chance to help health professionals, parents, teachers and others understand the things that are important to you.

Do you have good news stories or events for our next Newsletter?

Please contact Dorothy or Rebecca at: soecic@soton.ac.uk

Hellos and Goodbyes!



Hello, My name is Ewa (pronounced Eva) Guscott and I joined the SOECIC team as a Teacher of the Deaf in January 2012. My previous experience includes working in a School for the Deaf with the 11-18 age group, managing a Resourced Provision attached to a mainstream school with the 4-11 age group and, most recently, working as a Specialist Teacher Adviser right across the age range from 0-19. I am really enjoying my new role and look forward to meeting many of you in the coming months.



Hello, I'm Anna Lyford and I joined the team in February. I previously worked for Hampshire County Council Adult Services Sensory Team working with people with hearing loss and dual sensory loss. I am very proud to be working at SOECIC as I am a CI user myself and I am looking forward to helping you all get the very best from your implants.



Welcome back to Kirsty Carey. Kirsty came back to us in April 2012 after having her second daughter Evie in April 2011.



Hello! My name is Katrina Faulds. I'm an audiologist and although I've been at SOECIC a little while, you might not have seen me as I'm only part-time. In my spare time, I'm also completing a PhD in the music department at the University of Southampton. I really like working with cochlear implants and look forward to meeting more of you over the next year.



Hi, I'm Samantha Johnson and I joined SOECIC as a Hearing Therapist in March this year. I have previously worked as a Hearing Therapist at the RSH Hospital in Southampton and more recently I have been teaching lipreading classes at a number of colleges in Hampshire. Being a cochlear implant user myself I am delighted to be working here at SOECIC and I look forward to getting to know many of you in the future



Goodbye to Sarah Baumann as she takes maternity leave from June 2012. We wish her all the best and look forward to meeting baby Baumann!



Hi, I'm Ed Heard the new Clinical Support Assistant at SOECIC. I joined the team in January and I am now your main point of contact for all spares and repairs requests to do with CI equipment. I'm really enjoying the working environment here at SOECIC and it is a completely new experience for me as this time last year I was in an equipment management role in the British Army. If you ever have any equipment queries or need to request spares or batteries then please call the hotline on 02380 584068 or email us at soecic.repairs@soton.ac.uk and I will do my best to help you.



Goodbye to Margie. It finally happened and I'm retired! It has honestly been a privilege to work with all the families and children over the years. I feel that I got the best of the deal as I learned so much from you and got so much pleasure. Having wanted to be a teacher of the deaf since the age of eight, I can safely say that my career choice worked out for me. I still frequently think of the children on my caseload but try not to ask! And what's next? I plan to give myself time and not rush into anything, but am looking towards something that gives me a sense of achievement but doesn't require too much time commitment. Any ideas welcome!

Contact Us

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