

Newsletter

Issue 29 | Winter 2011 | South of England Cochlear Implant Centre

SOECIC is 21 in December

SOECIC carried out its first cochlear implant surgeries on two adults in 1990. In 1992 the first children were implanted and over the past 21 years we have been growing and changing to the point where SOECIC is now truly an adult!

Thinking back over the past 21 years the main changes have been in the external equipment; those of you implanted all that time ago will remember the old body worn processors. These were worn in a shirt pocket, in a harness, or on a belt. Nowadays the processors are relatively light and worn tucked away behind your ear. The internal device has changed less in its appearance but has many more capabilities than the older ones and they can deliver sound much more quickly and efficiently.

Twenty-one years ago no one thought that implanted people would be able to perceive speech as well as you can, appreciate music and even hear in background noise. This centre and researchers in the University of Southampton have been at the forefront of many of the UK developments in cochlear implantation; better coding strategies, bilateral implantation, accessories workshops, the development of music programmes and parenting courses for parents, these are only some of the many ways we strive to ensure you get the best you can from your implant. We will be having a 21st birthday celebration for past and present employees of the SOECIC before Christmas, some of whom have not seen the new building.



Save the date

January 28th 2012

You are all invited to join us for a big party in celebration of the 21 years of SOECIC.

On the day we will be putting together a 21st mural composed of pictures. We are asking if your children can draw an A5 size drawing about cochlear implants and SOECIC's 21st birthday party and send it to Nicola Cole, at SOECIC before 28th January 2012 or bring it along on the day. There will be the opportunity on the day to create a drawing.



Time for Change

The South of England Cochlear Implant Centre has rapidly expanded due to the steadily increasing number of patient referrals we have had over the years. The number of clinicians at the Centre has continued to rise to cope with the increasing workload. We are now a team of over 40 supporting almost 650 adults and children with cochlear implants.

With the aim of further improving our service the team has split into three smaller teams - East, West and Central, and the care of each individual cochlear implant user has been assigned to one of these teams. We have also made some changes to the frequency that we continue to see children and adults after their implant operation. We will continue, as always, to see patients at other times if requested. However, the planned reviews will be as follows:

Children:

Surgeons will see a child for at least 3 years after their initial tuning and until the child is 7 years old. The audiologists will continue to see the children and teenagers annually until they are 18 years of age when they will transfer to the adult programme.

Adults:

Adults will receive an appointment for an annual audiology and medical review for the first 3 years after their initial tuning and on the 5th annual review and at subsequent five year intervals from the anniversary of initial tuning. In all other years questionnaires will be sent to decide if a review is needed.

The new system started on 1st October and we are confident that this will offer better care for our patients and their families.

IMPORTANT: If you change your GP for any reason it is essential that you let us know your new GP's details immediately, please. If the GP on our records is not the GP that you are currently registered with we may not be able to send you any spares or arrange to see you. Thank you.

Well done!

Kate Tamin competed at the National Disability Trampoline Finals at the NIA in Birmingham during the summer holidays and took the gold medal for the third year running.



Congratulations

to Imogen Manuel who had her implant at the age of 10 and has done well at Lancaster University. She achieved a 2.1 in LLB Law and Criminology with Joint Honours.

The way I am

I am no different to what you are.
I am just like you, if you let me be.
I am who I am. I am me.
Only God can tell what he wants me to be,
For he knows, the way I am.
I am no different to what you say.
I can talk, just like you, if you let me.
I know what I can say. Even if the sounds
Of words aren't the same as yours,
Only God know, and can tell, what I am
Saying, for he puts all that's in my heart
Knowing that he is with me.
I am no different to what you hear and see.
I can hear just like you, if you let me, OR
Maybe not quite like that, Only God has
Made me hear things and see
This by giving me this important gift
And that gift was my first hearing aids
Knowing that God does care

As years gone pass, my hearing will no
Longer benefits from any hearing aids at all.
But God hasn't given up on me, for he will be
Giving me another chance, a chance, and other
Opportunities, and that will be a cochlear implant.
I will still be me, that who I am. I am going to hear
Something new, I am going to hear like you, if you let me
Give me a chance, one more time,
To be like you with my cochlear implant.
I'm no different to what you are, I am me.
And that will always will be
That who I am. GIVE OTHERS A CHANCE TOO.
Thank you for this wonderful gift
Me and my cochlear implant.

Audrey Lewis
(implanted August 2011)



Nina Goulden (née Wheeler) would like to thank everyone who supported her with her fundraising to compete at the badminton in the Deaf Olympics, Korea 25th October to 7th November 2011.

“Korea was amazing! I loved every moment of it. The badminton standard was incredible as a lot of countries play professionally. However, the GB men's doubles got through to the final against the Koreans and won a silver medal. I really enjoyed the team event more than the individual event. In the team event we just missed out on a bronze medal losing against the Bulgarians in the quarter final. I loved meeting deaf people from all over the world. It was a great experience and a wonderful opportunity.”

Richard Bizley wrote about his implant experience so far.....

"I was born profoundly deaf with some residual hearing. I had my cochlear implant operation in March 2010.

I have had a life-long struggle to live in harmony in a 'hearing' world, coping in schools for the deaf and at a boarding school, employment in various companies, starting my own business and now running a small gallery/shop where I work with the public daily - all has left me tired!

Having Meniere's Disease was the last straw and I am thankful to have the C.I. which takes off at least some of the burden that we as deaf people carry as we go through our daily lives.

I have no doubts that having the cochlear implant was the best decision I have made for a long time. I think the fact I gambled and had it done in my 'better' ear was the correct thing to do as it was deteriorating anyway.

I was pragmatic in my outlook and didn't expect too much, but already it has exceeded my expectations.

My first year can only be described as an amazing journey and I look toward to the future with greater hope and confidence, although I am aware that any improvements I am now getting have plateaued. I am realistic that I may never hear as much as a normal hearing person regarding speech.



Prior to my implantation, I was not able to understand a word from a radio. Now I have an MP3 player and I try every day to listen to the news. If I do manage to get the news it is incredibly rewarding. I am starting to listen to music, though so far it is limited but it is a start of yet another journey.

From my personal view what makes the whole experience as a C.I. user is SOECIC. The building is modern, welcoming and more importantly those wonderfully trained staff that work within. I always look forward to my next appointment. I really feel SOECIC's formula works well. It is great to be part of it via all the workshops/parties etc. I think it is good from a psychological point of view that SOECIC is not in a hospital.

How I envy babies and children having implantations at such a young age these days. It is marvellous to think their C.I. will help them enormously. I know this as I have been through it all, seen it all, having a C.I. is the best solution!"

The Money Maze

The way in which your cochlear implant and maintenance is funded may not be that familiar to you. We thought it might be a good opportunity to use the newsletter to explain this important but sometimes confusing process. When SOECIC receives a referral for an assessment for cochlear implantation we request funding from the Commissioning Group or Primary Care Trust which covers your area. This is not based on your home address but on your GP's postcode. There is a very useful website called NHS Choices which has a lot of information available to the public and which helps us identify which Commissioner your GP comes under. When it comes to getting funding for the actual cochlear implant we apply to them again with

a copy of the end of assessment report so funding can be approved. Did you know it costs just over £31,000 for a unilateral implant for an adult and over £46,000 for a bilateral implant for a child? These costs are all published on our SOECIC website if you are interested.

After the surgery SOECIC charges the Commissioner an annual maintenance fee on the anniversary of the first implant which covers all of the appointments, spares, repairs and upgrades. SOECIC charges a flat fee based on whether the patient is an adult or child and the number of years after the implant. These fees must cover all SOECIC's costs. A processor is around £6,000 to replace. Of course, accidents do happen and processors can be lost in

unusual places! So, if lost ones turn up we are always really happy. Even a coil and cable costs between £94 and £185 depending on the device.

We hope that the funding side of your experience has been relatively seamless and free from worry for you. We only ask that if you move house or go off to university or for any reason you register with a new GP that you keep us informed, as this might mean you then come under a different funding area. Sometimes the Commissioning Groups inform us that our patients have moved and then we have to refund money and track down the correct Commissioner to bill! Thank you for your help in this very important matter. We look forward to hearing from you next time you change your GP!

Jo gets on her bike for SOECIC!

Joanne Deacon, one of our adult cochlear implant users had a fantastic idea to celebrate the 21st birthday of the South of England Cochlear Implant Centre, and to raise much needed funds for new audiobooks for our adult patients and to help fund the making of a DVD to give new patients more information about SOECIC in a way that they can share it with their friends and family.

On Saturday 17 September four intrepid cyclists set off from SOECIC to cycle to Surrey to raise money.



In the photograph you can see two of our audiologists (Sarah Flynn and Guoping Li) who went along to support Jo and her friend Cheryl.

Jo wrote to us:

“It was a fantastic ride and the weather was gorgeous and the views lovely! Guoping was like a whippet and his top speed was 48mph according to Paul! We couldn't keep



up with him at times no matter how hard I tried! Special thanks to my husband Paul and Cheryl's husband Tony who made sure we were safe the whole journey. Cheryl took a tumble as the weather deteriorated as we got closer go home but got back on her bike, bless her. We started at 10.30 I think it was, and arrived home to a welcoming party of friends and family just before 4.30pm. We were cold

when we stopped and damp from all the heavy rain so warmed up with a lovely coffee in the Red Lion in Egham!



A special thanks to all those that sponsored us! Particularly to the companies too who made generous donations of £50. However, whatever we were sponsored for was greatly appreciated! We're still collecting but in December the figure was in excess of £800.”

Thank you

We have also had some very generous donations from patients and their families to help pay for resources, and towards the cost of the new DVD which is now available to all new patients on assessment . We will also have a link to the film on our website.

SOECIC governance board



Eva Newbury is the adult patient representative on the SOECIC governance board.

“ My name is Eva Newberry; I'm 46 working full time as a Quality and Operational Excellence Professional working for Virgin Media. I've been married for 27 years and have a 9 year old daughter. I have had bi-lateral cochlear implants for nearly 3 years. My left side was implanted first in 2005 when my daughter was three and a half. The right side was done 3 years later in 2008. They really have

changed my life allowing me to do my complex job and add value to my team and organisation. A lot of people benefit from my ability to hear, not just me, and my quality of life and those of people around me has dramatically improved. Having implants make it possible to hear life which is fantastic!

Eva Newberry

Email:

eva.newberry@virginmedia.co.uk”

Technology Update

Advanced Bionics - Neptune Sound Processor

Advanced Bionics has brought out a new bodyworn speech processor called the 'Neptune Sound Processor'. The Neptune processes sound in the same way as it does in the PSP (or Platinum speech processor) or Harmony but the main advantage of the processor is that it can be used underwater so it can be used whilst swimming or in the bath if the waterproof headpiece is used. The other advantage is that it is very small and light compared to the PSP. As with the PSP nothing is worn on the ear as the headpiece contains the microphone. The processor can be clipped to clothing or to your hair or can go in a pocket or even be clipped onto swimming goggles! It comes in a range of colours.



New patients will be given the choice of either the Harmony or the Neptune. Existing patients will be offered the Neptune when they are due for an upgrade (normally after 5 years of processor use). There are some recent patients who were given PSPs as loaners in anticipation of the arrival of the new processor. They will be contacted as soon as the processors are in stock and fully available.



The Neptune is compatible with all Advanced Bionics processors other than C1 implants. As with all speech processors it cannot be used with implants made by other



manufacturers (e.g. Cochlear or Med-el).

Could this be the end for Splitters?

Bilateral FM users have been using 'splitters' to send a single FM signal to two processors as Cochlear do not produce a bilateral FM cable.

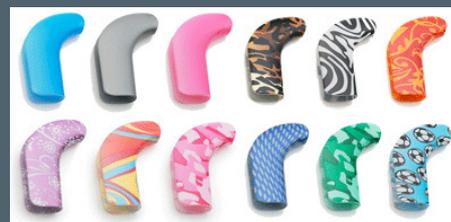


The splitter is ungainly and is liable to damage the socket into which it fits due to the increased leverage which could be applied to it.



SOECIC has developed and now produces a bilateral cable which is so much neater than the splitter.

Processor covers from Connevens



Implant users with CP810 Nucleus 5 speech processors can supplement the supply they get from SOECIC if they want to by purchasing them direct from Connevens. If you are interested contact: 01737 247571 or www.connevens.co.uk for £5.18 per pair

Having a second cochlear implant

In 2009, the Government brought out guidelines about cochlear implantation, called NICE guidelines. These guidelines state that since 2009 children can have two implants, if it is in their best interest. In order to cope with the level of interest from parents of children implanted before then who only had one implant, SOECIC has been considering all the children in waves, according to their ages and the length of time they have had their first implant. We are now finishing this process.

If you are interested in exploring an additional implant for your child please contact your Key Contact to let him/her know.

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

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

Hellos and Goodbyes!



After four very happy years I am leaving SOECIC to pursue a new career in Guernsey. As some of you will know this is where I was born and brought up so it is going to be wonderful to go back to my roots and live near my parents and other family members again. It has been a real privilege to work with my outstanding colleagues at SOECIC and I will miss them and all the patients I have got to know so well. I wish you all the best for the future. Nikki Stephens



Hello I am Helen Bolton and I am a new member of the admin team. As part of my role I will be organising assessment weeks for patients. I have previously worked in the NHS and I am a University of Southampton graduate. I am looking forward to working as part of the SOECIC team and meeting you all soon.



Hello! I'm Annabel Beales, SOECIC's Receptionist and Events Administrator and I joined the team in August 2011. I've come from an NHS background working in Southampton Healthy Schools. I've also previously worked as a Training Coordinator so will be fitting into my new role nicely as Events Administrator. I am enjoying working with such a close and friendly team!



Hi, my name is Michaela Rogerson. I am the new clinic secretary. I have previously worked at the RSH, SGH, The Nuffield and The Spire hospitals. I have enjoyed my time working in the health sector and am now looking forward to taking my career down a slightly different path working at SOECIC. I am excited to take on the new challenges and to get to know and work with my new colleagues.

Reminders:

Spares and repairs returns postage:

When sending equipment back to us please ensure that the correct postage is paid. If the postage is incorrect we have to pay for any postage shortfall plus an additional fine. If you are sending back a processor please send it special delivery with the maximum insurance (£2,500).

Cochlear implants and Ear Infections:

If you think you have an ear infection please see your GP as soon as possible as you may require a course of antibiotics. SOECIC can provide you with a letter written by our surgeons to give to your GP if required. Please contact us if you would like a copy of the letter.

999 EmergencySMS:

Did you know that the emergencySMS service lets deaf, hard of hearing people in the UK send an SMS text message to the UK 999 service where it will be passed to the police, ambulance, fire rescue, or coastguard. Simply by sending an SMS message to 999 you can call for help and the emergency services will be able to reply to you. You will need to register your mobile phone before using the emergencySMS service. To do this text the word 'register' to 999, then follow the instructions you receive. Alternatively, you can register online at www.emergencysms.org.uk

Contact Us

South of England Cochlear Implant Centre,
Institute of Sound and Vibration Research,
University of Southampton, Highfield, Southampton SO17 1BJ

Tel: 023 8059 3522 | Repairs Hotline: 023 8058 4068 | Text: 07887 790765
Email: soecic@soton.ac.uk | www.soecic.org

