



Issue 37 | Winter 2016 | University of Southampton Auditory Implant Service

Newsletter

A fun day was had by all who attended our Mad Hatters Tea Party Picnic on Saturday 17 September at Royal Victoria Country Park. Face painting, hat making and biscuit decorating kept the children (and adults!) entertained throughout the day. Games and activities such as croquet, giant jenga and egg and spoon races kept guests warm in the autumn air....and if they got too warm they could cool down with a refreshing ice cream from the ice cream van. Books and games were sold as well as donations for face painting. Over £500 was raised for our charity of the year Fisherman's Rest who support rural communities in Malawi. Thank you to everyone who came and donated so generously!

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Patient News

A parent's tips to customise your cochlear implant



MED-EL Music Grant

We are pleased to announce that Al Gardner (pictured above) is the winner of this year's MED-EL Music Grant. In his application he said learning any musical instrument has been beyond the capability of his hearing for 30 years and as a child he was never given the opportunity. Most of the time during his 25 years of hearing aid use music was an irritation that sounded like tearing paper off in the distance. "Since activation of my MED-EL cochlear implant I have done nothing but listen to music all day, I keep taking the hearing aid out of my other ear because I just can't believe what I'm hearing through my implant. The music is absolutely fantastic".

Al, who has used the money to invest in a guitar and guitar lessons said "I think it would be amazing to just be able to play a guitar well enough to entertain my friends around the camp fire, and after a year of professional lessons who knows what the limit would be."

Belle has always been a child who likes to stand out, and likes to be that little bit different. She likes what she likes, and doesn't let anybody tell her otherwise. In the early days with her hearing aids her glow in the dark bright pink moulds and glittery red hearing aids were an aid to help us find them when she 'lost' them, and the retainers helped to add a bit of extra security when on days out. For now she is all about being noticed, (and Belle loves people to notice and compliment her on her "ears") and her processor decorations match her bright sunny personality. Beautiful Belle's Bling are chosen by Belle to match her style and are hand-made by Belle's mum.

If you are interested in customising your processors or hearing aids, check out Belle's step by step guide.

www.mybeautifulbellesworld.com/belle-s-bling



Social event for Teenagers

We held another fun activity for teens in Southampton on 24 September 2016. Seven teens with cochlear implants came to try out Rifle Shooting at the University of Southampton Watersports Centre. A few of them had some experience at shooting already but it was a new skill to try for most of us. We were offered a whole range of guns to try out from a pistol to a large sniper rifle. Our instructor went through the various safety instructions and USAIS staff assisted by signing the instructions if required or demonstrating what to do next. Everyone managed to hit the target and most showed considerable improvement over the course of the afternoon. It all sounded complicated but once we had had a few goes it became much easier. It was great fun, lots of chance to learn and improve. We had some delicious pizza at the end sitting at the picnic table by the river and had a laugh posing for photos with the guns.

I am always looking to do fun events with teenagers. If you have any good ideas for future events do contact me, Rebecca Ricaud at rag@isvr.soton.ac.uk.



Coping with Tinnitus and returning to “The Light”



My name is David Caplehorn. I have been deaf, which is hereditary, since I was 33 years old. I am now approaching 70 and although I had some sound, I wore two hearing aids until three years ago, when I became a patient for a Cochlear Implant at the University of Southampton Auditory Implant Service.

I underwent the surgery at Southampton General Hospital during November 2013, without any problem and I do not remember having any pain at all after the surgery. However a couple of days later I became aware of tinnitus in my implanted left ear, it was a sort of gushing noise. I also had booms and banging which sounded like I was inside a tank and someone was banging the sides. It was distressing, as prior to the surgery and all the years that I had been deaf, I had never experienced tinnitus and knew little of the condition. I was not too concerned at that time, as I had been advised by the medical team that it was normal to experience some tinnitus after such major surgery and that it usually settles down after a few weeks.

In my case though it didn't settle down. The weeks went by, which turned to months and although the booms and banging noises stopped, I was still getting the gushing sound in my left ear. In the heading I talk of returning to the light, which is the way I see it. During the period I was waiting for my ear to heal all I could hear was the tinnitus, roaring, booming and banging in my left ear, a humming in my right ear and I descended into a very dark place indeed. My weight plummeted, I could not sleep and was petrified of being left on my own, in my mind I could not see how I would ever cope with it and the stress was going to kill me.

My wife had to work and one morning a few weeks after the surgery but prior to switching on the implant, she had left me sleeping. When I woke up I just panicked and emailed the Implant Centre pleading with

them, for Mr Hellier, the Surgeon, to remove the implant. Audiologist Sarah Baumann returned my email instructing me to go straight to the Implant Centre, where Sarah activated the implant. She was so kind and reassuring with me and at last I had sound in my ear, which although I did not realise it at the time, was the start of my recovery.

Even with sound in my ear I still could not come to terms with the tinnitus and listened for it all the time to see if it was still there. I visited my GP several times and even went to A & E on one occasion. Of course, the doctors tried to reassure me but could not help me other than prescribe sleeping tablets. I would not visit noisy places. I remember on one occasion my wife doing all the Christmas shopping on her own while I sat in the quiet of the car in the car park. As I had developed this fear of sound, I would mute the TV. On New Years Eve we watched the fireworks and celebrations with the sound turned off, even the fish tank had to go. On the other extreme I could not stand taking my processor and hearing aid out, as without sound all I could hear was the tinnitus. I would rush in and out of the shower or bath as quick as I possibly could and try to sleep with the processor in. I hated the implant and was so preoccupied with the tinnitus I did not realise how much my hearing had improved.

Then came, Mr Hellier, Louise and Samantha at the Implant Centre. My GP wrote to Mr Hellier, my Surgeon, who agreed to see me. He told me that sound was good not bad and that in time my brain would filter out the tinnitus and prioritise what it wanted to hear. Both Margaret my wife and I also had many emotional counselling sessions with Therapists Louise and Samantha. They gave me material to read and advice about keeping occupied, sleeping etc. All sorts of things to try to take my mind off the tinnitus. Just talking to them was such a help.

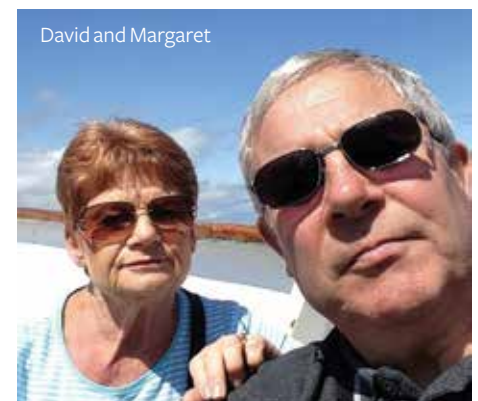
Margaret, our family, staff at the Implant Centre and our good friends, all realised how psychologically sick I was. They all played their part in my recovery. Counselling, visits at home while Margaret was at work, outings, texts, emails, anything they could do to take my mind off the tinnitus and bring me out of my dark place. I shall always be grateful to them all.

I gradually became less anxious about sound and visiting the Implant Centre for tuning

sessions. The tinnitus did not seem to affect my hearing and I was beginning to enjoy hearing new sounds as my hearing improved and with the Implant, I found I was able to join in conversations again, also music sounded pretty good. It came as a surprise to me how many people I know have tinnitus. “Yeah. I get this buzzing in my ear all the time” someone would say. I can't explain what a great help it was to me to know that they cope with it, without looking for causes.

One day I just told myself that this is me now, I will live with it. From then on I slowly recovered. I like to think that the tinnitus I am hearing are sounds within my own body. If anything helps me cope with it, it is this belief. I am at a state of mind now where I can talk about the tinnitus, laugh about it without getting anxious and totally ignore it. It is not there unless I concentrate on it and if you ask me if I still hate my cochlear implant, the reply will be, “Not likely, I absolutely love it!” My hearing now, is far better than any of my expectations.

As for life, I enjoy working again, being happy and being out and about in normal surroundings, even noisy environments. I listen to the radio, music and enjoy going to live performances on stage. My hearing has improved so much since I received the Implant and am very grateful to the Implant Centre for selecting me to receive one. The greatest hurdle I overcame was my fear of sound. The doctor I saw on my visit to A & E told me that twelve months from now you will be able to look back at today and say ‘I am ok now’. One year to the day after turning the TV down to watch the Celebrations and fireworks on New Years Eve, Margaret and I drove to Richmond, walked up into the Park and joined the crowds and watched the fireworks over London.



David and Margaret

Patient workshops

Our workshops aim to ensure you get the most out of your auditory implant. The Telephone Workshop gives practical guidance for cochlear implant users on how to use the telephone. We also offer a Tinnitus Workshop which goes through coping methods to cope with Tinnitus and a Voice Workshop which provides advice on healthy voice production.

If you are interested in attending please email AIS.Training@soton.ac.uk where you will be added to the waiting list for the next workshop.

Telephone Workshop

25 January 2017	27 June 2017
28 March 2017	26 September 2017
23 May 2017	28 November 2017

Voice Workshop

13 June 2017

Tinnitus Workshop

31 January 2017

Training

The University of Southampton Auditory Implant Service continues to run its popular training programme for parents and professionals with an interest in cochlear implants and other implantable devices. We run courses for professionals to help them when supporting patients with cochlear implants.

We know what a difference it can make when staff in schools feel knowledgeable about implants and how to manage the equipment. School staff are vital in helping children get the most from their devices and so please let your child's school know that these courses are available, and they can find out more via our website or email us for further information on ais.training@soton.ac.uk

Often these courses are free to those supporting USAIS patients and feedback from staff attending them has been excellent.

“This course covered everything I needed to know and more”

Patient Events

The Magic Ear Ball

In May 2017 a family with a bilaterally implanted teenager will be hosting a charity ball at their home in Hampshire. The Magic Ear Ball (so named as Agatha's hearing aids and then cochlear implants have been called this by her family since her birth) aims to raise vital funds for The Elizabeth Foundation, a Hampshire based pre-school for deaf children and their families where Agatha started her listening and speaking life at just 3 months old. We hope to raise money and awareness to fund a "Home Learning Programme". This is aimed to give families like the Tufnell's access to The Elizabeth Foundation's help and expertise, tailored to their individual needs, no matter where they live in the UK. We also hope to raise enough money to establish a network of outreach workers able to arrange visits and informative events that will help ensure that other deaf children are given the best possible support. Please, if you or your company feel able to help in any small way by either advertising in our programme or sponsoring, we would love to HEAR from you. Please get in touch with Katie Tufnell – k.tufnell@icloud.com.



Who would like more cheese?

Have you been lucky enough, like me, to go on a music workshop at AIS and enjoyed finding out more about listening to and making music with an implant? I had a great afternoon and very much enjoyed playing 'Cheese' the piece for African drums and would love to play more.

I am attempting to get a group of people together who would like to join a drumming ensemble initially for an afternoon in February or March and if we enjoy it perhaps to meet termly. Implantees and family and friends would be welcome, in fact anyone who would enjoy concentrating on rhythms and playing simple ensemble pieces for a couple of hours.

I envisage meeting in Fleet, Near Fleet Services on the M3. The costs would depend on the number of people who wanted to join but you would know how much before you made a commitment. There would certainly be time for refreshments and chat too.

Please email cidrumming16@gmail.com. I look forward to hearing from you.

Sarah Smith

Parent rep needed – Clinical Governance Board

USAIS has a clinical governance board which meets twice a year to provide advice and oversight of how it is doing and making sure that the best interests of its service users are being met. The board includes members representing auditory implant users. If you are over 18 and a parent of an auditory implant user, and are interested in becoming a member of the governance board, please contact the Director of USAIS, Carl Verschuur via C.A.Verschuur@soton.ac.uk. You will need to be willing to participate in twice-annual meetings which take place at USAIS early evenings.

AIS Plus

Self-Funded Cochlear Implant Service - Would you like a second implant?

At USAIS we are pleased to announce a new self-funding service that may be suitable for some of our cochlear implant users. Although the NHS does not fund bilateral cochlear implantation (a cochlear implant for both ears) for adults except in very exceptional circumstances, at USAIS we are now offering the possibility of a second implant via the self-funded route. This means that if you have already received one cochlear implant from USAIS, and are found to be clinically suitable for a second implant (in the opposite ear), you will be able to fund the second device and all the associated care at USAIS.

What can I expect from a second implant?

A first cochlear can offer some or all of the following benefits:

- Ability to hear and identify environmental sounds
- Improved lip-reading
- Understand speech without lip-reading
- Potential to use the telephone
- Increased confidence and independence in communication with friends, family and work colleagues.

The improvement with a second implant is 'not as dramatic' as for a first implant. It can help with:

- Locating where sound is coming from
- Making listening a bit easier in noisier environments
- Hearing when someone talks on the non-implanted side
- Less strain in daily listening
- A sense of hearing being more 'balanced'

There are a number of factors that can influence the outcome, including things like the cause of deafness, duration of deafness, hearing aid use and any cochlear/ear abnormalities or other concerns. These are all aspects that are considered as part of the assessment process.

Am I a candidate?

Potential candidates for the self-funded implant route are adults, resident in England, who meet the following guidelines:

- Severe to profound bilateral hearing loss
- Fit cochlear implant manufacturers' guidelines
- Conventional hearing aids are not suitable, or offer limited benefit
- Have worn a hearing aid/s consistently in the ear/s to be implanted

For consideration for a second implant, you need to already be a patient at AIS.

For more information

Visit our website or contact Mrs Fiona Jones (AIS Plus Senior Administrator) or Dr Nicci Campbell (Self-funded CI Team Lead) on ais.plus@soton.ac.uk or Tel: 023 8059 3522

Keep children safe from Button Batteries

Recommendations from the Child Accident Prevention Trust

- Keep products with batteries well out of reach if the battery compartment isn't secured with a screw.
- Keep all spare batteries out of children's reach and sight, ideally in a high-up, lockable cupboard.
- Avoid toys from markets or temporary shops as they may not conform to safety regulations.
- Teach older children that button batteries are dangerous and not to play with them or give them to younger brothers and sisters.
- Remember that even used batteries can be dangerous, so recycle them safely.

Stock and Equipment

Over the Christmas period USAIS will be running a reduced spares and repairs only service on certain days.

Outside of these hours please call and leave a voicemail, email, text or use the Spares and Repairs section of our website and we will respond as soon as possible.

Phone: 023 8058 4068 SMS: 07887 790765 Email: ais.repairs@soton.ac.uk

www.southampton.ac.uk/ais

Friday 23 December 2016 (CD)

Limited repairs cover 10am – 2pm (Slightly earlier closure due to xmas post)

Monday 26 December 2016 – Boxing Day (PH)

No Service

Tuesday 27 December 2016 – Christmas Day (Substitute Day) (PH)

No Service

Wednesday 28 December 2016 (CD)

Limited repairs cover 10am – 4pm

Thursday 29 December 2016 (CD)

Limited repairs cover 10am – 4pm

Friday 30 December 2016 (CD)

Limited repairs cover 10am – 4pm

Bone Conduction Hearing Implant News

New processors

New Cochlear Baha power and superpower processors have been launched based on the Baha 5. These processors are suitable for different levels of hearing loss. Baha 5 power processor replaces the BP110 processor and the Baha 5 super power processor which can be head-worn replaces the body-worn Cordelle processor. USAIS will be using the new Baha 5 range of processors with appropriate new patients. Existing patients will have new models of processor fitted in accordance with our upgrade policy. We are looking into options for the use of remote microphone technology with these new processors in educational settings.



Baha 5 Superpower

Baha 5 Power

Baha 5

New Clinical Commissioning Policy for Bone Conduction Hearing Implants (BCHI)

This new policy was published in July 2016 by NHS England. This relates to bone anchored hearing aids and middle ear implants. Some points are as follows:

BCHI and Middle Ear Implants (MEI) will only be available to patients who have tried conventional air conduction hearing aids and these are unsuitable or do not provide adequate benefit

Patients must have hearing loss within the manufacturer's fitting guidelines

Patients must have stable bone conduction thresholds

If you have any questions please get in touch with Sarah Flynn, BCHI Coordinator at ais@soton.ac.uk

Results of cochlear implant remote care project

Dr Helen Cullington, in partnership with University of Southampton Management School and Electronics and Computer Science, along with the University of Nottingham, Cochlear UK and service users. Funded by the Health Foundation.



Around 1,400 people receive a cochlear implant in the UK each year. Patients require lifetime follow-up in order for their implant to be checked and adjusted, and for rehabilitation.

Cochlear implant care is provided at one of 19 specialist centres in the UK, which may be several hours away from the patient's home, involving travelling expense, time off work and family disruption. We completed an innovative project to make

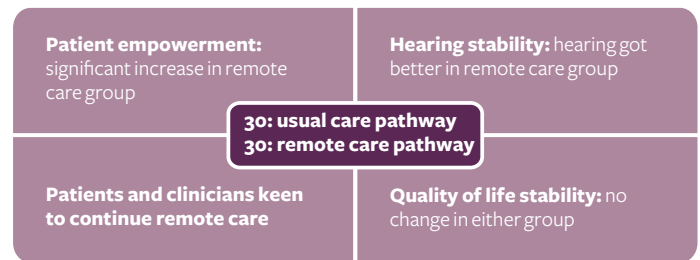
this care pathway patient-centred and provide a more efficient service to allow quicker identification of hearing problems. We designed, implemented and evaluated a long-term follow-up pathway for adults with cochlear implants, offering them remote self-monitoring, self-adjustment of devices, and a personalised online intervention package for testing their own hearing at home. The package of care included information, self-rehabilitation, advice, equipment training and troubleshooting. The customised remote control technology allowed people with a certain implant model to adjust their own hearing levels.

We enrolled 60 people using cochlear implants in a clinical trial, and randomised them to either the remote care group or a control group. The control group followed their usual care pathway. The remote care group were given some tools to care for their implant and hearing at home:

- Home hearing test on iPad or computer (Triple Digit Test)
- CIRCA online support tool for troubleshooting, rehab, info etc.
- Upgraded processor sent to home instead of clinic visit (if upgrade due)
- Remote assistant fitting for people with newer Cochlear device
 - ability to fine tune hearing with implant at home
- Access to additional rehabilitation tool (Advanced Bionics SoundSuccess)

The main outcome that interested us was patient empowerment; this is strongly linked to better outcomes in people with long-term conditions. We designed a new measure of empowerment for people with cochlear implants (the CI-EMP) to assess their beliefs, knowledge and skills to care for their own hearing with a cochlear implant.

We found that only the remote care group had a significant increase in their cochlear implant empowerment after using the remote care tools. The hearing test result in clinic improved in the remote care group, although they had not noticed a change. The control group, however, felt their hearing had become slightly worse. This may suggest that the remote care group were more able to take action to keep their hearing stable during the trial.



What did the patients think?

This was the first time that people using cochlear implants have been given remote care tools. What they told us about the tools is very important to shape what happens next. Here are some quotes of patients talking about what they liked about remote care:

“There are a lot of very interesting features, eg rehab and information that I will definitely use in the future”

“I have been using the enhanced controls to adjust my processor as I go along ... The adjustments help me to carry on rather than withdraw from a hearing situation”

“This is great I hope I do not lose this facility after the trial finishes”

“The CIRCA software. I chose using the telephone as my first goal ... Finally I must say how thrilled I was just to be able to pick up the telephone receiver without outright panic. I haven't lifted a receiver for some 40 years or so”

“I have been altering my implant quite successfully then doing a hearing test”

“First a whopping big thank you for the SoundSuccess. It fits so much with many of the thoughts I've been having.”

Future plans

Many people using cochlear implants would like to have more control of their own care and use tools at home. We are going to design a new long-term care pathway based on the results of this project. We have also had a lot of feedback that parents of children using implants would like to have more tools at home, so we will begin investigating this. Of course we will always provide care in the traditional way at the centre and we realise that remote care is not for everyone. We would like to offer care to people in the way that suits them best.

Sam and Anna's TOP TIPS

Next Generation Text Relay

Many of you will have had a go at using the telephone once you have learnt to use your implant – you may have attended one of our Telephone Workshops or used our Telephone Training Programme. It is really quite difficult to hear speech clearly on the telephone with a cochlear implant but sometimes, even in this day and age of text messaging and emails, being able to use a phone still has it's place. For many years, a 'text-relay' service has been available to help those with hearing loss. Technology has really driven developments forward and over recent months a new service has been launched to update the old 'Type Talk' service and make it compatible with internet-based platforms and therefore more versatile.



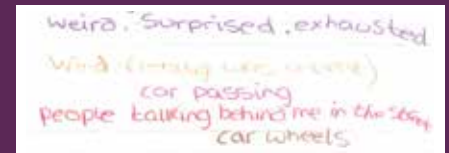
- If, on telephone calls, you can't hear the other person's voice clearly or don't catch all that they're saying, or they can't understand what you're saying, the Next Generation Text (NGT) Service can help.
- By using a smartphone, tablet, or computer and making a phone call you can receive a live transcript of the conversation via a relay assistant. Whether you use NGT at home, in your office, or on the move you can order takeaways, book taxis, use phone banking, order goods, or just chat by typing and/or reading your phone conversation.
- Can't hear clearly on the telephone - the relay assistants will type what the other person is saying so that you can listen to the speech and use your own voice but also read their words at the same time, like live subtitles.
- Not confident to speak on the telephone - type what you want to say and the relay assistant will speak your words to the other person whilst simultaneously typing back the response
- Still want to use a textphone/minicom - NGT works with textphones in the same way as the old Text Relay

The Next Generation Text Service website contains step-by-step guides to setting up the service on different devices, see www.ngts.org.uk for more information.

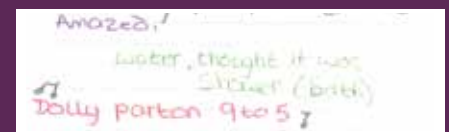
Patient News

John Gower, one of our cochlear implant users compiled a diary of the sounds he could hear with his implant each day. You will notice from the short extracts just how much change has taken place over a short amount of time.

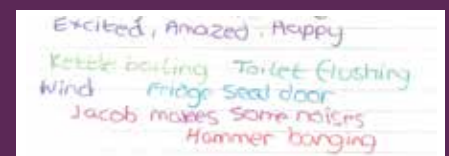
Tuesday 13 September 2016



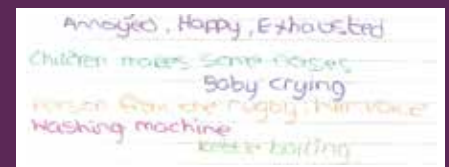
Wednesday 14 September 2016



Saturday 17 September 2016



Sunday 18 September 2016



Monday 3 – Sunday 9 October 2016



NGT Workshop

We are also running an NGTS Demonstration in conjunction with the National Association of Deafened People.

Monday 9th January 2017 10:30 – 13:00

You need to bring a Smartphone (a mobile which can access the internet) with adequate data and call capability and a strong wi-fi connection. We also request that you download the NGTS app beforehand so this does not hold up the training on the morning. Unfortunately, the service is not available on Windows-based smartphones.

Places are limited to 20 so if you would like to attend, please contact Coral Abraham at AIS.Training@soton.ac.uk to reserve a space.

Staff update

Welcomes



Mike Nibblett

My association with USAIS started in the early 1990's at Southampton General Hospital (SGH). After 21 years at SGH I left to take up a position with the local NHS Specialised Commissioning team and after a few months was asked to take on the commissioning contract for USAIS! In 2014 I decided to leave the NHS and take a gap

year – however part way through I was asked if I might be available to help with the USAIS NHS contracts. I joined in October 2016 and look forward to another year of intense negotiating, contract monitoring and helping the wider team in anything that involves contracting. If I'm not in the office, the likelihood is that I'll be at a racetrack, either as a volunteer Racemaker or simply as a regular race goer.



Liz Parker

Hello. My name is Liz Parker and I joined USAIS in September as a Rehabilitationist in the Central Team. I have been a Teacher of the Deaf for 18 years, working in oral/aural, Total Communication and Sign Bilingual settings. I have worked in Resource Bases in primary and secondary mainstream schools including

managing three bases. I have also taught in specialist Schools for the Deaf and been a peripatetic Teacher of the Deaf. I am excited to be joining the fantastic team at USAIS and look forward to meeting many of you in due course!



Melanie Dalley

Hello, my name is Melanie Dalley. I started working at USAIS in June 2016 and am thoroughly enjoying my role as Clinic Secretary for AIS Plus and BCHI. I have previously worked for ENT Consultants and other surgical consultants at the Royal South Hants as Medical Secretary and was a PA for the Director

of Nursing for Solent NHS. Prior to that I worked for 10 years at Southampton City Council as Senior Business Support Officer for Children's Services and Learning. In my spare time I am a dedicated salsa dancer. I look forward to meeting you.

Goodbyes



Pauline Cobbold

I am sad to share with you that I will be leaving USAIS at the end of September. It has been an amazing journey through the thirteen years I have worked at the Implant Centre. I have met so many incredible children and their families and watched them grow and develop their communication skills. I have enjoyed working

alongside local professionals, sharing knowledge and skills, and in our expanding multidisciplinary team here at Southampton. I have learnt so much working here. It has been a difficult decision to leave after all this time and I shall miss so many people. However the last time I stopped the world and got off, I trained as a teacher of the deaf... I wonder what fate has got in store for me this time?

Mark Chacksfield

We wish the best of luck to Mark, one of our Audiologists in the East Team, in his new role at Belfast Auditory Implant Centre.

Reminders

- **Long Term Questionnaire:** It is hugely important that those who have been implanted for over 3 years return their Long Term Questionnaire so we can keep our records up to date. This affects our funding from the NHS so it is vital that this is returned.
- **MRI Scans:** Are you aware you need to let us know if you/your child is scheduled for an MRI scan? This applies to whichever body part is being scanned. Cochlear implant users need certain safety precautions to be taken before an MRI is carried out.
- Please ensure that you keep your speech processor safe as it is NHS property on loan to you for as long as you need it. If you or a family member is no longer in need of the processor (for example if the cochlear implant recipient has passed away or has decided not to use their processor any more), please do return it to us.

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.

Contact us

Auditory Implant Service, Building 19,
University of Southampton, Highfield Campus, Southampton SO17 1BJ

Telephone: 023 8059 3522 | Repairs Hotline: 023 8058 4068 | Text: 07887 790765

Email: ais@southampton.ac.uk | ais.repairs@southampton.ac.uk

www.southampton.ac.uk/ais | [@UoS_AIS](https://twitter.com/UoS_AIS) | [f](https://www.facebook.com/AuditoryImplantService) AuditoryImplantService

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

Please contact

Coral at:

ais@southampton.ac.uk