UNIVERSITY OF Southampton

Newsletter

Issue 34 | Summer 2014 | University of Southampton Auditory Implant Service

Welcome to our new Director, Carl Verschuur

I am delighted to introduce myself as the new Director of USAIS. The last newsletter opened with Julie Brinton's farewell message, so you might be interested to learn that Julie finished on 31st December and I started on 1st January! Julie will be a really hard act to follow and I want to join everyone else in thanking Julie for her 17 years working for the service. I worked with Julie and a number of the current USAIS staff, and saw a number of the current implant service users, when I previously worked at SOECIC (as was) from 1999 to 2004. Over the past number of years I have been doing a mainly academic role next door to USAIS in the Hearing and Balance Centre, which focuses on audiology teaching and research, much of it related to cochlear implants. During that period, USAIS has expanded and changed almost out of recognition. One aspect that is particularly gratifying is that funding from the NHS has grown with the demand for services so that many more people across all ages are now able to benefit from this fantastic technology. I feel really privileged to now be able to lead the service forward.

Although it's early days in the new job, I've come with some definite ideas about how I'd like to see things develop. Both technology and medical knowledge move on so quickly, so I think it is absolutely vital that we at USAIS are leading in research and development in the area of auditory implants, but perhaps more importantly we should be applying that research for the benefit of patients. I am particularly interested in "hearing preservation", which means ensuring that whatever hearing the implant recipient already has before they receive the device is preserved as far as possible. The more we learn how to make sure that hearing and the structures of the inner ear can be preserved after getting the implant, the more people will be able benefit from the device. At USAIS we have also been at the forefront of introducing new technology and I'm keen that we continue to do this; over the next few years I'm hoping we can continue to develop better ways of tuning the devices and providing rehabilitation. I will also be working hard with others around the UK over the coming years to make sure that the current guidelines for who should receive a cochlear implant defined by NICE (the National Institute for Health and Care Excellence) are reviewed and updated with the very latest evidence to ensure that as many people as possible who stand to benefit from a cochlear implant are able to do so. Finally, I am keen to look at new ways we can involve you, the implant users and parents, to help us develop and improve the service.

I'm very much looking forward to meeting some of you over the coming months and years and wish everyone a very enjoyable summer!

Carl Verschuur

Katrina Faulds waves to the camera from the top of the tower

The USAIS team from L to R: Pete Hamilton, Michael Jack Vowles, Katrina Faulds, Lorna Leverett and Jan Hinks

USAIS Abseil the Spinnaker Tower

On Sunday 25th May 2014, a group of our staff, family and friends abseiled the Spinnaker Tower in Portsmouth to raise money for Hearing Dogs for Deaf People. Audiologist Katrina Faulds and Deputy Finance Manager of our Faculty, Lorna Leverett were joined on the descent by Pete Hamilton and Michael Jack Vowles - both husbands of USAIS staff members, and Jan Hinks, a Learning Support Assistant at a local Secondary School.

The abseiling team raised over £2,500 between them which, when added to our other fundraising efforts, makes a total of £6,500 for Hearing Dogs.

It's not too late to sponsor the team if you would like to. Please visit **www.justgiving.com/teams/aisdrop** to donate and add to our total for Hearing Dogs for Deaf People.

Patient Surveys 2013/4

Patients attending review appointments at USAIS are given a survey to fill in voluntarily to gain their opinions on the service.

We tell the patients:

The NHS wants us to ask you about your experiences on your most recent visit.

Your opinions are very important. The answers you give will help us to improve the quality of our service.

We would like you to think about your most recent visit and answer four questions.

Please ask if you are unsure how to answer the questions.

It would be helpful if you would give a reason for your answers as this will help us to make improvements.

Your comments will be anonymous but if you have a particular concern please do speak to a member of staff or ask to see your Team Leader or one of our Senior Managers.

Please either give your form to the receptionist or put it in the box provided.

If you do not wish to fill in the form today you can complete the form that is available on our website: http://ais.southampton.ac.uk/service-reports-and-surveys/

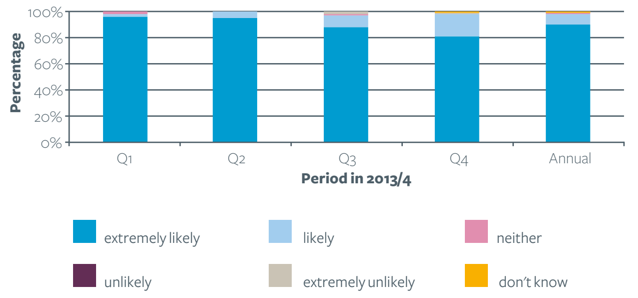
The following charts show the results of the patient survey.

Family and Friends

We began asking the following question in April 2013.

'How likely are you to recommend our service to friends and family if they needed similar care or treatment?'

How likely are you to recommend AIS?



The results were analysed every three months (quarter) as shown in this bar chart.

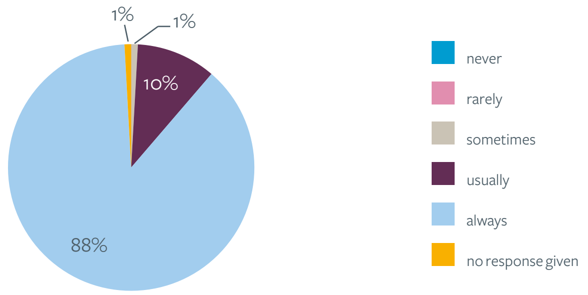
Overall 90% of USAIS patients responding to the survey when attending a review would be 'extremely likely' to recommend this service to their Family and Friends.

We exceeded the target that the NHS set us which resulted in additional funding of 150k.

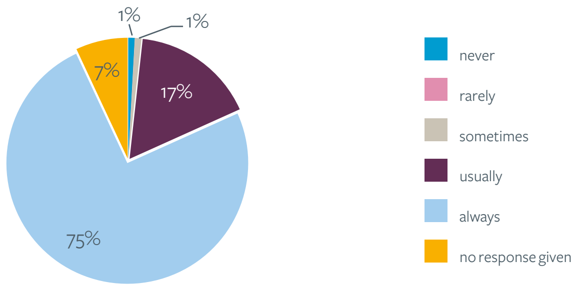
Thank you to everyone who took part in the survey.

In January 2014 we added 3 further questions and these are the results for the first 3 months:

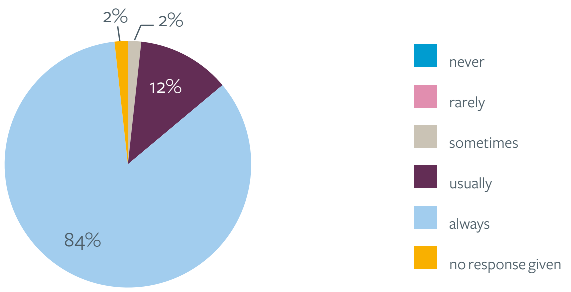
Do the Auditory Implant Staff treat you with Dignity and Respect?



Are you involved in decisions about your care/your child's care?



Do the Auditory Implant Service Staff work well together?



The IMAP helps CI users re-engage with music.

Programme launched to help CI users enjoy music again

A new computer-based music rehabilitation programme to help cochlear implant (CI) users re-engage in music and to hear music more clearly has been launched.

After three years of development and evaluation, the Interactive Music Awareness Programme (IMAP) was launched at the University of Southampton's Auditory Implant Service on the 30th January 2014.

The IMAP is a free, online music aural rehabilitation programme that has been developed with adult CI users through a series of consultations, music workshops and a trial. The new online IMAP now includes a larger library of music, featuring major artists such as Sir Cliff Richard and 10cc.

The programme guides the user through 24 half-hour sessions with written and subtitled video instructions on how to use one of over 20 interactive applications. These applications allow the user to create, manipulate and play music using different combinations of instruments, pitch ranges and rhythms. Each session ends with a mini online listening task (to help users discover new music on the web) or a fun test (to see how much the user has learnt).

The team behind this project include Professor David Nicholls, Drs Ben Oliver, Richard Polfreman and Ms Sarah Hodkinson from the Music department, Dr Rachel van Besouw and Mrs Mary Grasmeder from the Institute of Sound and Vibration Research, and Dr Mike Wald and Mr Magnus White from the Electronics and Computer Science department.

Dr Oliver says: "Cochlear implants can enable severely or profoundly deaf people to perceive sounds and understand speech. However, current devices are very poor at conveying pitch information and therefore, although many CI users express a desire to hear music again, many are dissatisfied with the way music sounds through their implant. We hope that IMAP helps CI users re-engage with music and recognise specific features through their implant, such as melodic pitch and the timbre of musical instruments."

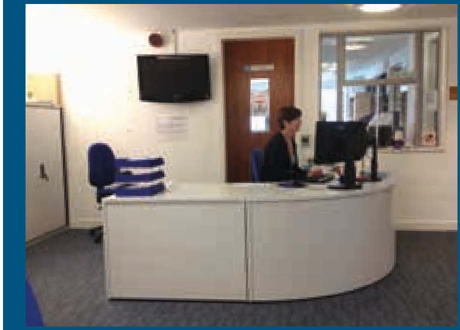
The project was funded by the Arts & Humanities Research Council.

For more information or to use the IMAP resource visit **www.morefrommusic.org**

New Reception Area

In April 2014 we refurbished our waiting area to try and improve your experience when you visit us. The biggest change is that we have moved our reception desk (and receptionist) into the waiting area rather than being inside the office. These before and after photos show what a difference it has made to the waiting area.

Before: The receptionist was behind a glass screen which sometimes made communication a bit difficult.



After: Now, it is much easier to talk to the receptionist.

Please get in touch to let us know what you think or tell the receptionist on your next visit. We have received lots of positive feedback so far and one patient told us they asked the receptionist a question that they wouldn't have asked before when she was behind the glass screen!

We are also waiting for a new children's play area to be installed which should entertain our young visitors whilst they are waiting for appointments.

Results from the Adult Voice Audit

Cochlear implantation may increase users' access to sound to an extent that allows monitoring and control of voice. Last year, in a group of 108 adults from our centre and the Emmeline Centre in Cambridge, we saw significant spontaneous improvement in adults' voice control in the first year after the operation. Some of you will remember helping us with this project. We reported these results at an international rehabilitation conference in the USA and the audience found them very interesting. They also wanted to know whether this change occurs in both adults with acquired and congenital loss.

As a result, we have gone on to look at voice control over the first year after operation in 29 adults with acquired and 34 with congenital hearing loss. The age range was 18- 88 years. We video-taped people's voices in vocal exercises and conversation on two occasions: pre-implantation and at the one year review. The voice of each adult was assessed by Speech and Language Therapists who categorised breath support, ability to switch the voice on and off, voice quality, control of pitch and range, use of loudness, articulation, use of rhythm, and intonation.

What did we find?

Both adult CI users with acquired and congenital hearing loss showed spontaneous development in voice control in the first year post-implantation. We found no differences between groups on breath support, articulation, ability to switch the voice on and off and voice quality in the first year. We did find some differences between the groups in control of voice pitch & range, loudness, rhythm and intonation

The group with congenital loss had lower pre-implant scores than the acquired group and at their one year review for more than half of the congenital group speech intelligibility was affected to some extent by reduced voice control. However, the congenital group made faster improvement than the acquired group over the study period and it will be interesting to see if there are still differences between the groups 5 years post-implant.

We video-taped people's voices in vocal exercises and conversation on two occasions: pre-implantation and at the one year review.

Personal Insurance for Speech Processors

Adele Dodd has written to us about her experience in insuring her son's speech processor.


Photo: MED-EL

Many patients have insured their speech processors

She says "I insured my son's speech processor with AXA in January this year after many conversations with them. My main reason with choosing AXA for my home insurance was that they offered the best price and cover for Jacob's processor. Before I took out the cover I called them and made sure they understood that I did not own the speech processor I was trying to insure and that it was in the hands of a four year old boy. AXA said it was no problem that I didn't own the processor I just needed to be responsible for it while it was loaned to Jacob. The insurance was under £300 which included building and contents insurance and accidental damage cover as well as insuring the processor inside the house and outside as well. Only a month after I took out the insurance Jacob flushed his processor down the toilet. I was devastated. I rang up AXA and they were brilliant. As I was so upset and because Jacob would be totally deaf without his processor, the lady at AXA said she would do everything she could to make the claim progress quickly. The next day Be Valued called me which is the name of the company who handles claims made for medical equipment. They said as soon as they received a quote saying how much it would cost to replace the processor they would put the money into my account. I contacted MED-EL and got a quote which I emailed to Be Valued and very quickly the claim was settled. In all Jacob was without his processor for just under two weeks. I was very pleased with this and incredibly grateful to the staff at AXA and Be Valued for paying the claim quickly and with no qualms at all."

Making a Splash

Three year old Owen has had bilateral AB Neptune processors for two years. His mum Katie and dad Martin chose them as they regularly go to the swimming pool with brother Alfie. Mum Katie has found attaching the processors in their aqua pouches to a back float has worked well, using long length aqua leads threaded between the float and his back.

Katie says

"Owen loves his processors and uses them with his back float every time we go swimming. We found using the arm bands provided by AB a bit difficult to get on with in the pool as Owen would easily pull his coils off while splashing about. He found this very frustrating! The back float is brilliant as it gives him free movement in the water and the coils hardly ever fall off. Owen listens very well in the pool and often responds better than Alfie."

Here is Owen modelling his back float.

CI Wear have created a swim and active wear shirt for cochlear implant users

Active Wear Shirt for CI Users

CI Wear have created a swim and active wear shirt that has sleeve pockets that allow individuals to incorporate their CI sound processors into the shirt. The shirt conceals the processor(s) within the sleeve pockets and allows you to thread the sound cord on the inside of the shirt. This reduces the possibilities for snags and entanglement when swimming or participating in different physical activities.

For more information please visit their website **www.ciwear.com**

Alternative Headbands for Children

In our last newsletter there was an inspiring piece on Hazel's bespoke headbands made by her mum to keep her speech processors in place. For those of you who are not so confident to give it a go yourselves there is a ready made option. Visit **www.hearinghenry.com** for more information

hearinghenry headbands are designed to keep speech processors on babies and toddlers, so they cannot be pulled off by wandering, curious fingers!

Middle Ear Implant – life after the op

One of our middle ear implant users, Steph Bennett, wrote to us recently about her implant journey.

"I have started this feedback so many times and every single time it came over like a report – so I am trying again and I am trying very hard to convey my wellbeing changes as well as the physical changes. 'Leading from my heart as well as from my head'.

A quick resume of me – mum of two teenagers; one with severe nocturnal epilepsy. In full time employment – I work in local government and am involved in policy decision making and liaison with members so lots of meetings, some that I chair at a Hampshire level and lots of listening required - not the best career choice for someone with hearing problems. I was required to leave my previous profession as a ship's captain due to my hearing loss. I have a hubby who is also hard of hearing.

I won't list the problems I was struggling with before my implant but will incorporate them into the changes to my life over the last 6 months.

I had my op at the beginning of 2013 and as the year has progressed I have experienced remarkable improvements.

I must start with a change that I did not expect, and that I don't think anyone anticipated. I have always been reasonably good at foreign languages and had not really twigged that as my ability to hear decreased my foreign language use decreased as I relied more on lip reading. But this year I have been to France twice. FABULOUS! I can actually converse; rustily mind you. Of course I couldn't lip read French, so I had withdrawn to being a bystander on holidays. It was like a 'Eureka' moment – I was stood at the butcher's counter and realised that I was actually conversing with him rather than pointing and gesticulating. I have two trips to France booked for 2014 and one trip to Greece; hopefully I will impress the locals with a bit of conversation.

The example above is significant in that it represents just one of so many things that have been unexpected. All have increased my happiness and wellbeing but that, in turn, has increased the wellbeing of those around me.

I return home in the evenings and whereas I would take my hearing aids out to give my sore ears a rest and become a recluse, I am now conversing with my family. I have started a bit of a social life by attending a big raucous quiz night in Bournemouth once a month. 280 people packed into a lively café. Noisy. Hilarious. Mindnumbing chaos at times. But I feel included.

I had been suffering terrible swelling, soreness, infection and bleeding from the skin inside my right ear for many years. The left ear was also quite unpleasant but less so than the right side that has always been very difficult to fit ear moulds to; for those reasons, as well as the medical reports expressing no preference for which ear should be implanted, we selected the right side. Since I have had the implant the right ear has settled down completely with no pain at all; but so has the left ear. In fact, the swelling in the left ear has reduced to zero and I now require another new ear mould as my present one is rattling around; the audiologists were astounded by how much my ear canal had opened up.

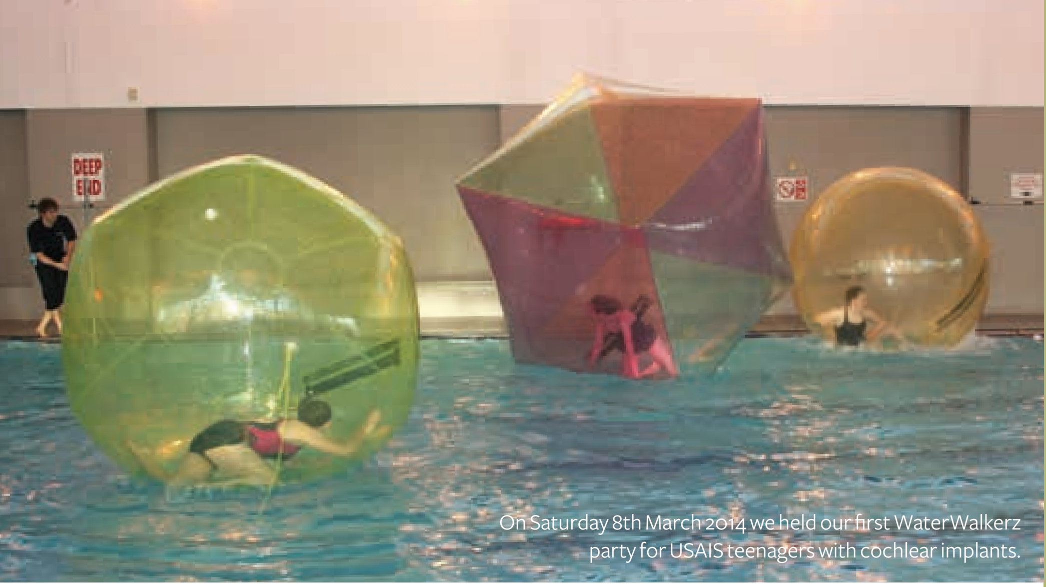
So I went from wearing my aids only for work to now being able to hear from the moment I wake to the moment I go to bed; this is where my family are getting their mum and wife back. I was so exhausted with trying to hear, coping with the pain and infections in my ears, and I suppose being really run-down and sad, that I was coming home, doing my chores and going to bed.

I probably should briefly mention my daughter Emma as together we have been through most things. Emma has nocturnal epilepsy so if we are going through a bad period I can sleep with the implant on. Her seizures start with a lot of noise so I now have a few more seconds to get to her before she goes into full seizure whereupon the alarms would go off. This allows me to help her keep her airways open.

I also want to mention something else I hadn't anticipated and that I believe is connected. I suffer with bronchiecstasis and had previously dreaded getting a cold. Even without a cold I ended up getting random lung infections. At the very least I would quite quickly be taking massive doses of antibiotics for infections in my lungs, at the worst I would be hospitalised as the infections and asthma affected my oxygen absorption. Since the implant I have not had a single lung infection. I have had bad colds and I have managed my asthma and breathing but I haven't ended up with an infection at all. The only thing that has changed is my previous truly revolting ears are now healed. I believe my lung infection reduction and my implant are connected.


Steph Bennett

So in summary how can I describe the change in me? I enjoy things. I am not ostracised at work by squeaking hearing aids. I feel part of life again. I am picking up and running with things that have needed sorting for some time that I have not had the energy or inclination to tackle. I am not looking inwards at me as soon as I finish work; my family have mum and wife back. I am so happy. I can hear. I can hear more. I can hear in meetings. I think I might do my PhD."

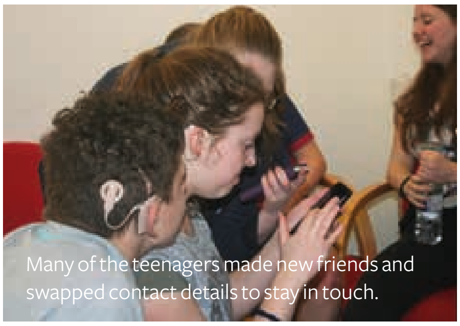


On Saturday 8th March 2014 we held our first WaterWalkerz party for USAIS teenagers with cochlear implants.

WaterWalkerz Teens' Event 2014

On Saturday 8th March 2014 we held our first WaterWalkerz party for USAIS teenagers with cochlear implants. 14 brave teenagers and 4 USAIS members of staff came to the Jubilee Sports Centre at the University of Southampton. Many had never tried the WaterWalkerz before but all were keen. Communication by various means carried on even when all of the teenagers had to take off their speech processors to go in the water. We took it in turns in groups of 3 to have a go in the WaterWalkerz. The rest of us got to have fun in the shallow end with the floats and balls. There were 3 types; a ball, a cube and a 'lightbulb'. It was fun bobbing about on the water in your own little world. We had 5 minutes per go in the WaterWalkerz as it needed lots of energy to get it moving around the pool, a bit like a hamster on a wheel. It was amusing to try and bump into each other. The lifeguard reeled us in when our time was up. It was hot inside the balls so it was refreshing to plunge back into the swimming pool afterwards. The real enthusiasts got a second turn. WaterWalkerz certainly works up an appetite so the pizza, cakes and fruit went down a treat after we had got changed. Many teenagers exchanged phone numbers, Facebook details etc. whilst we enjoyed our food. Some of the feedback included: 'Awesome', 'funny', 'I had a great time chatting with new friends', 'it was really funny' and 'I like to meet deaf people'. It was great to see everyone enjoying themselves especially considering most of them didn't know each other before they came.

I am always looking for fun activities for teenagers with cochlear implants so do contact me, Rebecca Ricaud, with any suggestions on R.A.Ricaud@southampton.ac.uk.



Many of the teenagers made new friends and swapped contact details to stay in touch.

New! Spares and Repairs Page on our Website

We have added a 'Spares and Repairs' page on our website where you can request a stock item, read troubleshooting guides and find our contact details. You will find this page by clicking 'Spares and Repairs' on the left hand menu of our website.

Here is what one of our patients had to say about the new way of requesting spares and repairs:

"It was nice and easy to use! Would definitely recommend, it's a lot more convenient, can be done at anytime any place!"

As always we welcome your feedback about our spares and repairs service so if you have an idea of how we can improve it please let us know.

Spares and Repairs Service Reminder

Hi! I just wanted to write a few lines to remind everyone how important your help is when we are dealing with your stock and equipment issues. We are always happy to send out replacements for broken equipment but please make sure you send all broken items back to us as soon as possible so we can get these repaired or replaced.

Please contact us by text, phone, email or use the form on our website. By providing us with as much information as possible you will enable us to help you in the quickest possible way.

There are some exciting developments with processor waterproofing solutions coming from both Cochlear and Advanced Bionics that will enable you to use Nucleus 6 and Naida processors with confidence in and around water. Keep an eye on the manufacturers' and our own websites for more details as to when they are available and how you can access them (USAIS won't necessarily be providing these items).

Please don't hesitate to get in touch with any issues you may have and I hope you have a great summer.

Ed Heard
Clinic Support Officer

Reminders

MRI Scans

Are you aware you need to let us know if you/your child is scheduled for an MRI scan? This applies whichever body part is being scanned.

Cochlear implant users need certain safety precautions to be taken before an MRI is carried out.

Medical Alerts

Are you aware you can order an emblem (jewellery, wrist watch) for you/your child? In case of emergency this emblem will alert the medical professionals about your cochlear implant. There are two options, the first option is a paid service with an annual subscription charge from **www.medicalert.org.uk**. In case of emergency the medical professionals will phone the medicalert team and get the details about your cochlear implant from them.

The second option comes with a one off charge from **www.universalmedicalid.co.uk**, where your emblem can be engraved with any details you wish (e.g. name, ear implanted or any contraindications associated with CI).

More details on these services will be advertised on our website in the near future.

Technology Update

Data logging capabilities with Cochlear's CP910 (or N6) and Advanced Bionics' Naida CI processors

Data logging is now available with Cochlear's latest processors – the CP910 and CP920 and Advanced Bionics' Naida CI processors. Both companies have come up with a similar 'Data logging' facility. Data logging is a useful tool for clinicians as it can show us which programme is being used the most, how much the processor is being worn and what sort of noise environment the CI user has been in. When a CI user with a CP910 (or N6) or Naida CI processor attends an appointment at USAIS and their processor is connected to one of our computers, the data stored on the processor is downloaded from their processor onto our computer. The data logging information is then available to the clinician. This information is useful to the clinician as it helps us understand if the CI user is making the most of his or her cochlear implant. The information could be helpful for tuning the device or for counselling. This data logging feature is not available for other speech processors as yet.


Photo: Advanced Bionics

Data logging is a useful tool for clinicians


Photo: MED-EL

MED-EL have designed a 'Sports Headband' to keep the Rondo or Amadé processors in place.

Sports Headband from MED-EL

MED-EL has recently brought out a 'Sports Headband' designed specifically for their Rondo and Amadé speech processors. It is made from microfibre material and is designed so that the processor fits in an integral pocket over the implant site so that it is more secure during sporting activities. The microfibre fabric also protects the processor from sweat and moisture. It comes in 4 different sizes. If you have a Rondo or Amadé processor and are interested in having one please contact USAIS.

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.

Hello from new team members

Hi, My name is Nicola Timoney. I started working at the University of Southampton Auditory Implant Service in January as an Audiologist within the East Team. I previously worked as an Audiologist in Portsmouth for 5 years and have thoroughly enjoyed the transition to my new role working with cochlear implant users since joining the service .

Hello. My name is Alex Archer and I am a new Speech and Language Therapist working in the West Team. I joined USAIS on 28th February, the same week as moving house and I'm already feeling at home in both! In my first few weeks I have been shadowing and learning, meeting and greeting and really enjoying getting to know the patients and families that I will be working with.

Contact us

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www.southampton.ac.uk/ais

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

Please contact Katherine at: ais@southampton.ac.uk