

MAKING CONNECTIONS

SUMMER NEWSLETTER 2017



YOUR EXPERIENCES

When you were going through the assessment process for your cochlear implant, you may have attended a recipient experience group (sometimes referred to as a user group). These groups receive very positive feedback as an opportunity to meet others with a similar hearing history and ask questions, however visiting the centre is not always possible or practical.

Therefore USAIS has been working on an exciting project to bring this experience online. Working with a variety of our service users we have created an online platform where you can hear the personal stories of those who went through this process. There are

also videos based around specific themes such as the assessment phase, operation and initial tuning.

We would like to say a huge thank you to all of our wonderful volunteers for making this possible. Currently we only have footage from adults but are looking to expand our video library to include more adults as well as parents in future. If this is something you would be willing to help with then please do get in touch.



Find out more:

www.aisexperiences.soton.ac.uk



USAIS IN THE NEWS

In the last 12 months USAIS has been trying to raise awareness of the benefits of cochlear implants for those with hearing loss, working closely with the media, companies and our cochlear implant users.



Life on mute

USAIS supported the MED-EL Life on Mute roadshow and one of our Audiologists conducted hearing tests on members of the public to raise awareness of hearing loss, which was picked up by local newspapers and radio.



The Robinsons

USAIS made local and national news with a feature story about a couple implanted and 'switched on' at the service at the same time. The story was picked up by BBC South Today, BBC Radio Wiltshire, the Daily Echo as well as the Daily Express, Daily Mail, The Mirror, The Sun and the Metro.



Remote care project

Dr Helen Cullington has been promoting the work of her remote care project for cochlear implant users and has been featured in Science Daily, Audiology World News and That's Solent TV.



BBC 4 Sound

A service user and one of our Audiologists were featured in a BBC Four documentary called Using Sound. The documentary featured an initial tuning session conducted at USAIS.

International Cochlear Implant Day

On 26 February 2017 USAIS celebrated International Cochlear Implant Day by posting on social media a selection of success stories from patents with cochlear implants. One of our adult cochlear implant users was also featured in the local newspapers for her own story about how her cochlear implant saved her life.



BONE CONDUCTION HEARING IMPLANT NEWS

Patients with bone conduction hearing devices may meet Audiologist Zoë Bevis or Rehabilitationist Liz Parker when they come to the centre for appointments. Liz and Zoë have been working with cochlear implant patients at USAIS for some time and have now joined the bone conduction hearing implant team as well.



Zoë Bevis



Liz Parker

SERVICE UPDATES

Have your say

Your feedback is important to us. We would like to encourage all of our service users to complete the feedback form either on our website or on the iPad in reception when you are next in clinic.

This feedback is constantly monitored and used to improve our service.

Find out more:
ais.southampton.ac.uk/contact-us/have-your-say

Accessible Information

We want to communicate with you in the best way possible.

If your communication needs have changed please let us know. We can send you a form to complete with the options we can provide, including Interpreters, Large Font, Easy Read Format, Braille or any other communication needs.

We follow the NHS Accessible Information Standard which you can read more about on the NHS England website.

Find out more:
england.nhs.uk/ourwork/accessibleinfo

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OUR NEW LOGO

The University of Southampton Auditory Implant Service is one of five units based within the Faculty of Engineering and the Environment Enterprise Zone.

The Enterprise Zone has been re-branded to introduce logos for each of the units and you may have noticed our new logo on the bottom of your letters or on our social media.



HEARING FOR HOCKEY



Carine Shergill is 14 years old, with bilateral cochlear implants and she is a keen hockey player. Hear how her deafness has not stopped her pursuing her passion.

I am profoundly deaf. I have two implants, one Advanced Bionics and one Cochlear. I have played multiple sports: swimming, hockey, tennis, karate and cricket. I don't play any of those sports anymore apart from hockey. Hockey is my life now and my best sport. I have been playing hockey since the age of seven and hated it then but as I grew older playing more and more, I started to enjoy it passionately. I love it so much now.

As I went up the age groups to u14s, I was nominated to be put into the JDC (Junior Development Centre) and then got through to JAC (Junior Academy Centre- Berkshire). These stages are trials to get into the England hockey team. Unfortunately, that year, I didn't make it into the Berkshire team. However, I didn't let that hold back my desire, so I kept going. I redid the trials again this year and got through to JRPC (Junior Regional Performance Centre) and got into the team to play the competitions. Unfortunately, I didn't get through to the next stage. Still I was not going to let that stop me from trying more and more. So I'm back training again this year

and doing lots of match practices and I am committed to keep going.

I think that deafness and hockey can still go together but the only negative I find is having to wear hair grips on my implants to stop them from falling off whilst I'm running or if I get pushed over. I never used to wear the hair grips, but now I do because I realise now that's one of the things that is going to help me isn't it? I don't let anyone use my deafness as an excuse to not play hockey, including me!

My hopes for the future are to be part of the England hockey team and to play ladies 1's for my club.

"So my message to everyone is don't listen to what other people think, do what you love!"



JULIE'S STORY

My name is Julie. At the age of 42 I contracted meningococcal meningitis the results of which left me totally blind, totally deaf in my right ear and with about 40% hearing in my left ear. As you can imagine this all came as something of a shock. My balance had been greatly affected and it took me some time to learn to walk again as well as try to conquer the fear that came with being deaf and blind.

I was rebuilding my life to the best of my ability but four years after the original illness I suffered a complication and overnight my remaining hearing vanished. I cannot begin to explain the depths of despair and fear. I was totally in darkness and the only form of communication was to write letter by letter slowly on my hand.

Within a couple of months I was referred to see Mr Hellier. I am sure it was a challenging appointment but with the help of my husband writing on my hand he told me that he would try to help me. In the months that followed my original appointment a tiny bit of hearing returned in my left ear. I was fitted with a power hearing aid. The initial setup involved wearing headphones and a box on a strap around my neck. It was horrific and sounded awful.

The staff at the Cochlear Implant Centre at Southampton went above and beyond the call of duty to help me throughout my assessment process and afterwards. It was quite a challenge for them to be able to show me how to change my microphone by pushing out a tin pin with

a mini screwdriver. This was all done prior to the operation so that I could choose which processor would suit my needs.

I have to tell you that I was petrified about having the operation. My previous hospital experience involved two weeks on a life support machine followed by intensive care and rehabilitation. In early December 2012 Mr Hellier carried out the operation at Southampton General. Although the operation was a success my overnight stay in Southampton was a nightmare. They did not really cope with the challenge of having a deaf and blind patient.

The audiologist and coordinator from Southampton came to my house in January for the switch on. I was so lucky. After five years of total deafness in my right ear I now had sound. They had to retune it three times before they left the house because I was greedy for sound.

I have now had an implant for four years and I cannot begin to explain how it helps me to get on with life. Without the visual distractions I am totally dependent on sound. I have found that I have started to be able to communicate again in both French and Spanish and last year we went travelling in Asia for seven weeks. It was a bit of a challenge to find a back pack that would not knock the cochlear off my head.

I think my greatest achievement since having the CI was to be brave enough to fly unaccompanied with just help from airport staff.

The most fascinating sound I have experienced was on Safari in Kenya for my 50th birthday. I listened to a blow by blow account from my sons who were watching a hyena hunt a gazelle. Once the hyena had caught the gazelle we were nearby and I could hear it crunching on the bones!

The difference in being deaf as well as blind is vast. There are times when sound can be so over whelming and I have no visual way of seeing where it comes from. I do function better in a tranquil environment and in a noisy situation such as screaming children on an airplane my husband is jealous that I can simply turn off my implant.

I think that my implant has been such a success because I have to use sound instead of sight. I use a talking phone, talking computer, talking tape measure, talking colour reader and voice labels in the kitchen. My implant is in overdrive for about 16 hours a day.

"Thank you does not cover the appreciation to the staff at the Implant Centre. I am eternally grateful."



Read more of our inspiring patient stories
<http://ais.southampton.ac.uk/category/patient-stories/>



SWIMMING WITH SOUND

Abi was fitted with a Neptune processor not so long ago, as a gift from Advanced Bionics as a Bionic Ear Association (BEA) mentor, so she could experience hearing in water for the first time! She wears the Neptune in her hair when swimming.

'One particular "wow" moment was at the water park going down the shoot on a rubber ring with Matilda sat behind me. I could hear her giggling behind me, lovely moment. I could relax so much more. And as we were there for most of the day I wasn't plunged into the usual silence I could have conversations.'

HANNAH'S STORY



My name is Hannah and I am 19 years old. I received bilateral cochlear implants in the summer of 2014. I am currently on a gap year and will be going to university this coming September.

I have actually been assessed for cochlear implants twice in my life, once at around the age of five and then again more recently at the age of 16. I have a progressive hearing loss and was first diagnosed as moderate to severely deaf at the age of two, receiving my first hearing aids just before my 3rd birthday. When I was five, I had a CT scan and along with other tests, it was discovered that I have Enlarged Vestibular Aqueduct Syndrome as well as Pendred Syndrome. These conditions are the cause of my progressive loss and the associated vertigo. Vertigo not being the fear of heights, but a severe balance illness which came in the form of sudden attacks for me.

At a young age I had several vertigo attacks which also coincided with drops in my hearing, but my hearing also fluctuated, so sometimes it would return a little bit. It was for this reason that I was originally rejected for cochlear implants. Being such a young age I didn't really understand what was going on, so it didn't affect me so much. Eventually, the vertigo seemed to stop and my hearing stabilised, albeit at a profound loss on both sides. I continued on through life doing well at school. I achieved good GCSEs: five A*s, three As and one B, which I was very proud of because it had taken a lot of effort through school both academically and with support through notetakers and radio aids.

My next step was sixth form where I chose Biology, Geology and Geography as my A-levels because I want to become a Zoologist (Zoology means 'the study of animals'). I settled in well for the first few months. Unfortunately, the vertigo returned out of the blue one morning along with a drop in my hearing- this attack lasted for three days before I began to recover. Eventually, I went to my audiologist who confirmed the drop in hearing and was able to adjust my hearing aids

so that I could make the most of my remaining hearing. I returned to sixth form as quickly as I could because I have always hated missing school and did my best to continue with my studies. I had several more drops in hearing and some vertigo attacks too over the next few months which made education increasingly difficult and also affected my confidence. Eventually, I was referred by my audiologist to the Auditory Implant Service to see whether a CI would be for me.

This time I met the criteria, though I was borderline initially but after one more big drop in hearing which left me with pretty much no useful hearing left, I decided that cochlear implants were worth going for- I had nothing to lose anymore! I researched CIs extensively, I wanted to understand exactly what they were, how they worked and what other people's experiences were. The actual process of agreeing to have the operation and then having it done was very quick for me because there was a cancellation and also I had had another drop in hearing, so there wasn't much point in waiting around. This meant that I ended up having the operation in the Summer of 2014, a day after my 17th birthday.

The operation was successful but I felt pretty unwell for a few weeks afterwards. Despite this, I was determined not to miss the start of the second sixth form year so I went in for the first week with no hearing at all. A week later, it was time for the switch on. I didn't know what to expect, I was a little afraid that it might hurt. Thankfully, it was painless as beeps and whines filtered through. I couldn't really hear meaningful sounds but I could tell people were talking though the beeps were delayed as my brain tried to make sense of things. The first sound that I recognised was that of a tap dripping in the kitchen when I arrived home that day! Over the next few weeks and months I had lots of appointments to programme my new implants, these went well and it was a relief that everything had worked as it should. I was finding it hard to cope with everything that was going on though, particularly at

sixth form where I was trying to concentrate in lessons while hearing new sounds- who knew that writing on paper was so noisy! I was pretty exhausted and the decision was taken that I would drop two of my A- level subjects and concentrate on one for my second year. Therefore I ended up doing all of my A- levels over three years, but I achieved results that I again was really proud of because it had taken a lot for me to get them. I got two As and a B.

I have always been interested in science and nature from a young age with the zoology passion really coming through in my mid to late teens. Having CIs has actually increased my enjoyment of wildlife because I can actually hear more of birdsong now, even to the extent that with practice I can distinguish between a handful of different bird calls. Also, one of my favourite sounds has to be the snuffles of wild animals, which I hear on trail cameras that I set in my local area to watch foxes and badgers.

"CIs are an amazing technology and my hearing is much better with them, however, they are not a miracle cure by any means and I wouldn't want them to be."

I still really struggle in crowded and noisy environments and I heavily rely on subtitles and notetakers. In my case, a significant benefit is that due to the nature of my hearing loss, CIs have stabilised my hearing and I know that I should not have any more drops in hearing. Additionally, since having the operation, I have had no more severe attacks of vertigo - whether this is directly related to the operation I don't know and probably will never know. However, I am hugely thankful to the team at USAIS and my family as well as others who have supported me through this difficult and, at times, traumatic journey!



Read the full story on our website
<http://ais.southampton.ac.uk/patient-stories/>



MADELINE'S WALK

From left, Geoff Smith, Madeline Gronland and Lorraine Gerrish at the flat walk finish line in Shide.

Congratulations

Congratulations to Madeline Gronland who participated in "Walk the Wight" for Earl Mountbatten Hospice.

Her extraordinary determination has been celebrated by her friends and support workers after she

completed the walk.

Madeline Gronland, 70, was escorted along the eight-mile route by her gardener and close friend, Geoff Smith.

He said, "I started out as her gardener but I am now her friend. I take her out for little walks

occasionally. I told her we were going to do the flat walk and she could not wait for it."

Madeline was deaf from birth but has regained some access to sound since having cochlear implants. However, she is now completely blind, due to a degenerative eye condition.

Geoff added: "She loved it and she is raring to go again. She is sad its over."

Madeline agreed she was proud of her medal and said: "I did not want it to end."

AFRICAN DRUMS

In the previous newsletter we advertised the drumming workshops organised by Sarah Smith, one of our cochlear implant users. Hear from Sarah about how the first session went and future plans.

African drums are beautiful instruments. They are carved from a hollow length of tree trunk and beautifully patterned on the outside. The tops are cowhide and all have a mellow sound when tapped. As each one is a different size there are a variety of tones and most importantly all react well with a CI.

Just before Easter I was privileged to be part of a group who enjoyed an afternoon of music making on these beautiful instruments. Four of us had CIs another seven were from a deaf group and the others were family and friends who had come along for the fun.

Our tutor Luke knew we were adult beginners and would not like to show ourselves up in front of anyone and taught us accordingly. We learned to tap the edge of the drum and to slap the top. We played a long unison piece using question and answer word patterns, and then had a break for coffee and chat. It was good to meet other people who wanted to make music and find out their experiences. After the coffee break we moved onto playing and played a piece based on African countries and then played a game using our names. Finally our tutor, Luke played us a solo by request. It was a great afternoon for those who want to get back into playing post implant. The verdict was when can we do it again?

If you would like to be kept informed of future plans please email me on cidrumming16@gmail.com.

Sarah Smith





SAM AND ANNA'S TOP TIPS

Have you ever thought about joining a lipreading class?

Whether you are newly implanted or had your cochlear implant for many years, recently lost your hearing or have a long term hearing loss, there is much to be gained from joining a class.

Lipreading (or speechreading) is the ability to recognise the lip shapes, gestures and facial movements of the person you're talking to, in order to get a better understanding of what they are saying. It is a vital communication skill.

Although many cochlear implant users find they are more relaxed during communication and less tired at the end of the day compared to before they had their implant, a change that may be attributed to the reduced effort needed for communication; supplementing sound with visual clues is still important especially in less than ideal listening conditions.

We can all understand speech better if we can see the speaker's face, particularly in a noisy environment. However, to become a good lipreader requires skill and concentration as many words look similar on the lips (try saying these words in the mirror without using your voice and you'll see what we mean: man bad pat.) A lipreading tutor will

help you build on your existing skills.

Lipreading classes are the best place to learn to lipread. ATLA (Association of Teachers of Lipreading to Adults) provide information on the availability of classes (see www.lipreading.org.uk). Classes are informal, friendly and taught by a qualified tutor. You will learn about the different shapes that sounds make on the lips so that you can identify them, how to fill in the gaps of speech that you can't hear and how to use clues from the context of the conversation. As an added bonus, classes can be an ideal way to meet other people with a hearing loss in a safe and welcoming environment. Although attending a class is the best means of learning to lipread, there are some online resources available if you are unable to access a class. Take a look at www.lipreadingpractice.co.uk to get started.

Do contact Sam or Anna if you would like further information or advice.



Contact us:
02380 59 3522
ais@soton.ac.uk

TRAINING AND WORKSHOPS

Professional Training

USAIS continue to run their training programme for local professionals supporting our auditory implant service users. As part of our commitment to ensuring that all patients have the correct support we have now expanded our training portfolio to include our bone conduction hearing implant service and our auditory processing disorder service. We run training days throughout the year from basic to advanced level, so please make sure that the professionals supporting your child are aware of this opportunity for professional development. Details of courses can be found on our website and booking can be made online or by emailing AIS. Training@soton.ac.uk. We also offer bespoke training for teams across the South of England and are finalising an online training portal to make training more accessible for all. If you have any suggestions of future courses or opportunities that might be beneficial we would love to hear from you.

Tinnitus Workshop

We will be running our next Tinnitus Workshop on 11 October 2017 here at USAIS. It is open to all adult implant users who have been implanted for more than six months who experience tinnitus. The aim of the group is to learn about tinnitus and ways to manage it. If you

would like further information about the group, or to register your place, please contact Samantha Johnson (Hearing Therapist).



Contact us:
02380 59 3522
ais@soton.ac.uk

Me and My Cochlear Implant

We held our first 'Me and My Cochlear Implant session' for teenagers attending their Audiological annual reviews on 31 March 2017. Seven teenagers attended the session. The session was run by one of our psychologists, a teacher of the deaf and an audiologist. It was based on a workshop run in schools by the team of ICTODs (Implant Centre Teachers of the Deaf) at Guy's and St Thomas' Hospital. It was great for the teenagers to meet other implanted teens who were in similar situations to their own. They had the opportunity to find out more about their implant/s and share their experiences of deafness with the others. An unexpected bonus was that the parents all really enjoyed meeting and chatting with each other in the waiting room – we even had to find them a room so that they could keep going! Overall, I think that the teens gained a lot from the experience. We plan to run the session again for another group so do look out for the invitations.

STOCK AND EQUIPMENT

We need your help!

When a patient has a problem with a processor our aim is to get any processors that need replacing out to patients within 24 hours. The biggest obstacle to this happening is a lack of spare processors available in clinic for us to send out. Where you come in to this process is that we need you to return any faulty processors that you may have to USAIS as soon as you are able to. When it's possible we'll always send out a silver Royal Mail Special Delivery envelope that is pre-paid to get the equipment back to us. This service cost us £3265 in postage fees last year and we provide it on the pretext that it improves the return rate of loaned processors.

Lost processor policy.

USAIS aims to replace any lost processors as soon as possible. If an implant user loses a processor, this must be reported to the police and USAIS must be provided with the police report number as this might lead to the processor being recovered. Implant users are responsible for taking good care of their processors. We encourage implant users to use retaining equipment for the processors in order to avoid processors being lost. Children should use retaining equipment all of the time and adults should use it for particular activities such as sport. In the event of a lost processor implant users or their parents will need to complete the lost processor form and send it to USAIS. We will not be able to send any further replacement equipment or batteries until this form is received by USAIS.

HEARING LOSS SUPPORT

There are several local groups in your area who can offer support for hearing loss. Whether you are looking for online support, meeting up with other auditory implant users or support for your child, below are just some of the options available to you.



National Deaf Children's Society

The NDCS offer a variety of events around the country for parents of cochlear implant users. They also have a directory of local groups on their website.



The Elizabeth Foundation is a national charity supporting infants and pre-school children with hearing loss and their families. It helps babies and children with all degrees of hearing loss learn to listen and speak.



DELTA is a national organisation, offering support and information for families of hearing impaired children, who wish to follow the auditory route. They also run summer schools for primary and pre-school children.



The Ear Foundation

The Ear Foundation provide a service to bridge the gap between clinics and the local community, providing family and education programmes, information days and other events.



Cochlear Implanted Children's Support group

CICS is independent, voluntary group run by parents whose children have cochlear implants to help others whose children already have implants and those who are considering cochlear implantation for their child.



National Cochlear Implant Users Association

The sole association in the UK that represents all Cochlear Implant users. On their website they signpost to some local support groups including:

CI South west
Home Counties Cochlear Implant Group
CI Five Counties (UK)
Action on Hearing Loss Hear 2 Meet groups



#HearingLossHour

On the first Wednesday of every month between 1-2pm GMT, a twitter conversation takes place using the hashtag #hearinglosshour. The theme changes monthly and is a good opportunity to discuss tips with other people who have hearing loss.

OUR STAFF 20 years +

Congratulations to Mary Grasmeder (Clinical Scientist), Julie Eyles (Clinical Scientist), Sarah Flynn (Clinical Scientist) and Sarah Paganga (Speech and Language Therapist) (pictured left to right) who are all celebrating over 20 years service at USAIS. This achievement was acknowledged by the University of Southampton who presented them each with an engraved glass bowl. We are very grateful for all their hard work during their time at USAIS.



Hellos



Sarah Woods

My name is Sarah Woods and I joined the team in January 2017 as a Teacher of the Deaf. Previously I was a Teacher Adviser for Portsmouth Local Education Authority in Hearing Impairment, Visual Impairment and Multi Sensory Impairment. I have also worked in both Primary and Secondary Multi Sensory Resource bases in Portsmouth as well as an Infant Hearing Resource base here in Southampton. Prior to this I was a Primary School Teacher for 10 years.

I have been made to feel so welcome by all the staff here at USAIS and I am excited to learn and develop in my new role. I look forward to meeting you all in the near future.



Judith Brennan

My name is Judy Brennan and I am the new Clinic Secretary for the East Team in Southampton.

I have 15 years' experience as a Medical Secretary in a GP surgery environment and trust this will enable me to fulfil my new role effectively. I have returned to working back at the University of Southampton, having first worked here 35 years ago before going on to do a variety of administrative and secretarial roles prior to having my family.

I love working in a clinic environment and am looking forward to working with the East Team and their patients.

Goodbyes



Wendy Stanmore

Farewell to Wendy who has left USAIS after 13 years of service as Clinic Secretary for the East Team.

Katrina Faulds

Congratulations to Katrina who has accepted a full-time three year post with the University Music department after completing her PhD in 2015. We will miss Katrina greatly but hope to still see her face around campus and at our popular music workshops.



Barinder Samra

Congratulations to Barinder on his new job as an International Audiological Trainer in Copenhagen. He will be greatly missed by staff and patients alike but we wish him the best of luck on his new adventure.

Maternity News

Congratulations to Caroline Gamble on the birth of her baby daughter. We also welcome back Louise Lee who has returned from maternity leave after the birth of her second daughter.

REMINDERS

Let us know if you can't make it

Between October 2016 and March 2017 **176 appointments** were not attended by patients. It is really important to let us know whether you can or cannot attend your appointment with enough notice, as each appointment not attended costs us time and money. You can let us know by text, telephone or email.

Change of contact details

Please keep us informed if any of your contact details change including your address, email or mobile phone number so that we stay connected with you.

MRI Scans

Are you aware that 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 procedures to be taken before an MRI is carried out.

Checking skin under the magnet

It is a good idea to check that the implant user's skin is healthy under the magnet on a weekly basis. If any of the following are present please contact the implant service for advice:

- Redness
- Soreness
- Pain
- Swelling

IMPORTANT

If you change your GP for any reason it is essential that you let us know your new GP 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



Thank you to Jack Mansfield who carefully designed, hand crafted and donated this piece of artwork to USAIS. Look out for it next time you are in reception.



Thanks to generous donations USAIS now have a picnic table outside the centre. Please feel free to use it to eat your lunch or take a break and get some fresh air between appointments.

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

Contact Coral:
ais@southampton.ac.uk

Is there something you don't understand?

We're happy to help.

Contact us:
ais@soton.ac.uk



Contact us

www.southampton.ac.uk/ais

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