

# MAKING CONNECTIONS

SUMMER NEWSLETTER 2019

## 'CONNECTING FOR LIFE' AT COCHLEAR IMPLANT CONFERENCE

The University of Southampton Auditory Implant Service (AIS) hosted the recent British Cochlear Implant Group (BCIG) conference. This annual event brings together a range of motivated individuals to highlight the latest clinical work, research and education for improving access to sound.

Researchers and clinicians united under the theme 'Connecting for Life' for the cross-disciplinary meeting, which showcased the best national and international research in the rapidly developing field.

The conference marked the start of an important chapter for the professional community, following recently updated guidance from the National Institute for Health and Care Excellence (NICE) which will mean that hundreds more people with severe to profound deafness will be eligible for cochlear implants each year.

Professor Carl Verschuur, AIS Director and BCIG 2019 Host, said:

"We are very proud to have hosted the 29th British Cochlear Implant Group Meeting at a



time when a much larger number of people will be able to benefit from this life-changing technology than ever before. By 'connecting for life' we can explore new ways to improve access to sound, support life-long use of cochlear implants and maximise outcomes for all our patients."

Around 230 people including international speakers attended the event's six sessions and Graham Fraser Memorial Lecture on Thursday 4 and Friday 5 April at The Spark in Southampton city centre.

# KATIE'S STORY

BY KATIE HOWARD-JONES

I was diagnosed as profoundly deaf aged 4. Nobody knows why. I was lucky as I was able to attend mainstream school. After sixth form I completed a drama course at Reading University and obtained a distinction in a BTEC National Diploma (Musical Theatre).

In 1992 I started my nursing training in London. I loved my time as a student nurse but I unfortunately did not come across senior nurses who failed to understand how I could be a nurse due to my deafness. This was quite upsetting and made me even more determined to prove them wrong!! I passed my finals first time and started my first job on a busy A&E admissions ward where I spent my last fantastic placement as a student nurse.

My cochlear implant journey began in April 2017 after I realised my high pitched frequencies had deteriorated when working in the Emergency Department (ED). Although I was delighted I was suitable for an implant, I really struggled with my decision and which ear and device to go for. However I received a lot of support from the AIS team. It was not until I met a few members from the SoCo group in November 2017 that I made my final decision. They were very positive and inspiring and made me realise this is what I need to help me to hear better.

On March 7th I had my surgery at the Nuffield Hospital, Chandlers Ford. I was very nervous but everyone at the hospital was kind and reassuring. After seeing my Consultant (Mr Mitchell) the day after the surgery I was able to go home. At my two week post-op check up I decided to set myself a challenge to return to ED nursing within a year.

I returned to work 4 weeks after my surgery, even though I couldn't hear much! Six weeks after my surgery I returned to AIS for my switch on. I had already been advised to keep my expectations low and not to expect too much too soon. The first sounds I heard were beeps when my family spoke to me. I was then aware of the sound of people breathing which I found rather amusing. On the way home I became aware of the sound of the car indicators and tried to listen to the conversations in the car but it was all beeps and sounded very robotic. The day after my switch on I was in the garden and my implant was beeping away. I realised it was the birds and I was so happy to identify this new sound!



“My rehabilitation journey was challenging but I kept pushing myself. My family helped me with identifying sounds and I had amazing support from AIS. I recently attended the telephone workshop and I am looking forward to streaming calls to my processor soon.”

I made a pact with myself to start as I mean to go on and to wear my cochlear implant processor from the minute I got up until I went to bed. However I had days when my head felt heavy and overloaded with learning new sounds. On those days I took it off for an hour.

Gradually over the next few weeks with further mapping and communication support the beeps gave way to sounds and words. One big issue for me was tinnitus. I had no idea this could happen. I attended the tinnitus workshop at AIS. This was very helpful and I learnt to identify triggers for my tinnitus and coping techniques which have really helped.

My rehabilitation journey was challenging but I kept pushing myself. My family helped me with identifying sounds and I had amazing support from AIS. I recently attended the telephone workshop and I am looking forward to streaming calls to my processor soon.

I still have good and bad days. Bad days are usually due to tiredness and the challenges of other people expecting too much from me and my cochlear implant. I love musical theatre but unfortunately for me it all sounds rather screechy and metallic still. I hope that in time this will settle.

Good days are for example the lady in the bank telling me my speech is much clearer and my family being delighted I can hear sounds I could not hear before. This is getting better all the time.

On March 5th 2019 I passed the challenge I set myself. I did my first shift as a bank nurse in the Emergency Department. Since then I have done more shifts and I love it! I am very grateful for all of the help from the team at AIS.

# TONOTOPIA: LISTENING THROUGH COCHLEAR IMPLANTS

BY SARAH BAUMANN

Back in 2016, Artist and Composer Dr Tom Tlaim invited six cochlear implant users from across the UK to meet with him at the V&A Museum in London to take part in a sound art study called 'Tonotopia'.



Tom had become interested in how CI users listen to music and other complex sounds through a digital device, designed to focus on speech, which completely bypasses the normal hearing mechanism. He had heard that music could sound unpleasant or harsh through a cochlear implant, so he wanted to explore sound and music to co-create unique soundscapes.

During the project, Tom spoke with each CI user in detail about their memories of sound pre-implant and then their unique experiences of listening through their cochlear implant. He asked the group to listen to a range of sounds and music in different ways and take part in exercises making sounds together. In response to the stories and descriptions he heard, Tom

created pieces of sound art incorporating some of the sounds and themes that were raised during the conversations and music-making sessions. He also collected objects donated by the participants.

In collaboration with Action on Hearing Loss, the V&A and supported by the Heritage Lottery Fund, Tom put together a display entitled 'Tonotopia: Listening through Cochlear Implants' which was exhibited at The John Lyons Charity Community Gallery from October 2018-March 2019. This included videos of the personal conversations, the pieces of sound art he had created and the personal items collected.

Sarah Smith, one of our adult CI recipients, took part in the project and kindly invited me to attend the launch event with her back in October 2018. Despite having worked with many CI users during my time at the USAIS, it was still fascinating to hear the stories and experiences of the six individuals who had taken part in the project. Also, to see how Tom had taken insight from the people he spoke to, to create his pieces of sound art.

The display at the V&A has now closed, but we are hoping that it may transfer to a local exhibition centre in the future... watch this space! In the meantime, please take a look at further information including the videos recorded on [www.tonotopia.org](http://www.tonotopia.org).

# SOCO SUMMER UPDATE

A huge welcome to all our SoCo members far and wide; new and old! The Southern Counties Cochlear Implant Support Group (affectionately known as SoCo!) continues to go from strength to strength. We are now 18 months old and our membership is now well over 200!

All our members continue to support one another fantastically online and at our hugely popular and regular socials. The support is much appreciated for the CI journey: choosing a brand, preparing for the operation, rehabilitation, sharing the successes and challenges. We have noticed a fabulous chain reaction in our groups whereby a new member might join, seeking information and support pre implant. Once implanted, they then support other new members who are considering implantation. This is a fantastic culture and is what makes SoCo so warm and wonderful.

SoCo has developed a helpful website and established good links with the Auditory Implant Service in Southampton. The website contains great information - useful for anyone considering an implant, progressing through

the assessment process or preparing for the operation itself. We also have an email address for those who don't use Facebook.

Our group members are families and individuals mostly from the Southern region of England including Dorset, West Sussex, Wiltshire and Hampshire. We also proudly have a few hearing dog members too! In 2018, we met at pubs across our region in: Portsmouth, Chichester, Salisbury, Winchester, Southampton and Portsmouth again! We reserve quiet locations without background noise and with good lighting... But it soon fills up with lots of chattering people with a wealth of experience between them. The most valuable part of joining a SoCo social is; no one minds "pardon" or repeating sentences. We truly have all been there... And are still there!

Last November, we had a Technology Day, giving attendees the chance to learn more about each brand and meet with their Reps; a very informative day. And in March we were delighted to be asked to give a presentation with Dr Helen Cullington at the British Cochlear Implant Group conference in Southampton on the topic of The Role of Social Media Peer Support in Cochlear Implant Care. It was wonderful and uplifting for soCo to share information about our lovely group and to be recognised for the important contribution we play in helping each other through our CI journey.

For 2019, we plan to continue our socials across the Southern Counties; hopefully every two months, including Fareham on 13th July. If you'd like to come along, please contact us. Please see our Facebook or website for further details.

Our Facebook Group [www.facebook.com/groups/cisoutherncounties](https://www.facebook.com/groups/cisoutherncounties)  
Email [cisoutherncountiesuk@gmail.com](mailto:cisoutherncountiesuk@gmail.com)  
Our website [www.cisoutherncounties.wordpress.com](http://www.cisoutherncounties.wordpress.com)

We really hope to meet you soon, regardless of if you've had your implant a week, ten years or are waiting for one! Please do pop along and say "Hi"!

The Admins; Caroline, Sandra and Sarah.



## MESSAGE IN A BOTTLE

We are pleased to let you know that we now have bottles available here at the Auditory Implant Service. If you are having an assessment for a hearing device, you will be offered a bottle at one of your initial appointments. If you have not received a bottle and would like one, please do ask!

It is a simple idea designed to encourage people to keep their basic personal and medical details on a standard form in a common location – the fridge! Simply write your details on the form provided and put one green sticker on the fridge and one green sticker on the INSIDE of your house door.

All Emergency Services are aware of the Message in a Bottle scheme, and by displaying the green stickers in your home; the emergency services will look in the fridge to find your details. Use the form to let them know you are a hearing aid or Cochlear Implant user!



# SUPPORT THE ENGLAND DEAF FOOTBALL TEAM

My name is Luke Bryant and I am 25 years old. I've been a cochlear implant patient for 21 years. I want to tell you a bit about myself and my football.

I am Public Relations Manager for England Deaf Football Men's Team. I have been working in International Deaf Football for ten years, started coaching Great Britain Deaf Women's Team at the age of 15. It is a massive achievement for me to be in this position and there are many questions I have been asked by people; I have one phrase to answer all questions - 'See the barrier, break it down and achieve your dreams.' I love my position in the England Deaf Football Team, it is a huge responsibility but the priority for my job is to make sure everyone has a smile on their face! I am on my way to the European Deaf

Championships with the team this June in Heraklion, Crete - facing other brilliant teams to try to become the one and only champion of Europe. That is my aim, to ensure the team win the trophy and bring it back home!

It is really difficult for the team to make their trip successful because we are self-funded with no funding support from the National Governing bodies. That is my job to work on fundraising by organising events, inviting supporters to attend matches, selling raffle tickets for prizes and much more. During my work, I ensure all the people who meet us

have a laugh, we want everyone to have an enjoyable and fun time. We want children to look up to the players and officials and make their dream to become one of us. Without this, where would we stand?

If your child dreams of becoming a deaf footballer, why not come along and meet our players and management team, have a great time, watch the football, take pictures and get autographs from the players! Please contact me - [ljbryant.edft.18@gmail.com](mailto:ljbryant.edft.18@gmail.com) - I am more than happy to help you in any way. We are one country, one team, that's England!



# TRIP TO THE HOUSES OF PARLIAMENT

BY ELLIE WHEATLEY

On the 30th of January my class, the Foxes, went to London by train for a very important trip. We learnt about politics for our topic this term so the trip to the Houses of Parliament was a very good way to see what we learnt.

The Houses of Parliament are having lots of renovation because they are so old so there was a lot of scaffolding up and the clock doesn't chime at the moment. The clock is called Big Ben but the tower in which it sits is called the Elizabeth Tower. We had a tour from a guide who showed us the House of Lords too. We were not allowed to sit on the seats because only Lords can do that! We had lunch with our local MP Steve Brine and everyone in the class was allowed to ask him a question, his answers were very good. He then told us we had some special surprises. We went to the Speakers house and then we walked underground and went to Downing Street which looked just like it did on TV. Theresa May was meeting Jeremy Corbyn we were allowed a tour of Number 10. I was speechless because it was so beautiful. There

were lots of amazing pictures in it, lots of Prime Ministers' pictures on the stairs but other ones too. Thank you to Steve Brine for showing us around, we felt very lucky. I felt especially lucky because I got to hand a Report to Steve Brine who is the Public Health minister and to the Prime Minister's Health Advisor. He has told us it has gone to the Health Minister already.

A note from Ellie's mum: the CMV Action research paper entitled "Counting the Cost" has been launched and was what Ellie gave to Steve Brine. She was also on ITV Meridian News as were many other families in different regions trying to raise awareness of Cytomegalovirus (CMV) as a leading cause of Deafness which may be preventable with simple advice to pregnant women.



## NEW TECHNOLOGY

Advanced Bionics recently released a new accessory option for the Naida Q90 speech processor. It is called the 'Connect' and allows patients to stream telephone calls and audio from any Bluetooth compatible device (any mobile phone, tablet or television that has Bluetooth enabled). It fits on to the standard 170 size battery.

This will be available as an option for all new AIS patients that choose an Advanced Bionics cochlear implant and those upgrading to the Naida Q90. For any current Naida Q90 users; it is possible to purchase the Connect from Advanced Bionics.



**If you have any questions please contact us on:**

[AIS@soton.ac.uk](mailto:AIS@soton.ac.uk).

More information can be gathered from the Advanced Bionics website.



# INTRODUCTION TO LIPREADING - A FREE 10 WEEK COURSE AT USAIS

Lipreading is a vital communication skill for many people with hearing loss. It involves watching and recognising the lip shapes and facial movements of a person speaking in order to gain a better understanding of what they are saying.

Everyone lipreads and watches a person's facial expressions without realising it, especially in noisy situations. Becoming a good lipreader, however, requires skill and concentration, and a great deal of practice as many words look similar on the lips. A lipreading teacher will help you to tell the difference between words.

"I have a cochlear implant. Will I benefit from improving my lipreading skills?"

A study by researchers at the University of Nottingham measured cochlear implant users' brain activities while lipreading and found that "the more a person's brain became responsive to lipreading, the more it also became responsive to sounds delivered through their cochlear implant, and the better they were able to hear."

USAIS Hearing Therapist, Samantha Johnson, is also an experienced lipreading teacher and will be running a 10 week "Introduction to

Lipreading Course" at USAIS on Thursday mornings from 10.00 to 12.00 starting on 3rd October 2019.

This course is free of charge\* but we do ask that you commit to the full 10 weeks. Places are strictly limited and bookings are being taken now.



**For further information or to book your place, please contact Samantha at USAIS.**

Email: [s.j.johnson@soton.ac.uk](mailto:s.j.johnson@soton.ac.uk)

Telephone : 023 80593522

SMS : 07887 790765

You are welcome to join this course at whatever stage you are at on your cochlear implant journey. Depending on numbers enrolled, the course may be opened up to local hard of hearing organisations.

\*A small voluntary contribution towards refreshments will be requested.



**Introduction to Lipreading**  
Ten week course

## LISTENING SUPPORT AT THE THEATRE: AN AUDIT BY NICOLA SHEPPARD

In a Rehabilitation session, a patient discussed her experiences of the listening support available at her local theatre with me. To that end, I contacted a number of theatres across the south coast to ask what listening support they have in their booking halls and auditoriums. Of the 66 questionnaires sent out, 25 replied. 2 theatres replied to say that they were no longer operating as theatres. Of the 25 that replied, 4 had listening devices available in the booking hall and 21 had listening devices available in the auditorium. A couple of theatres were awaiting new equipment after having refurbishment. As a result of the questionnaire one theatre said that it had "rekindled" their investment in an assistive listening device for their theatre.



# CHARITY UPDATE

## SKYDIVE

In memory of 3 year old Ayesha, a patient at the University of Southampton Auditory Implant Service, the team decided to raise money for the charity Meningitis Now.

The fundraising kick started with a cycle ride from Bath to Bristol last year and on Sunday 24 March 2019 three staff members leapt out of a plane at 13,000ft. Suzanne O’Gara (Audiologist), Anna Duncan (Speech and Language Therapist) and Mary Hamilton (Teacher of the Deaf) were joined by Ayesha’s dad, Avais and his friend, Harpal at Netheravon in Wiltshire for this adrenalin fuelled plummet to earth!

So far (including gift aid) the team have raised just over £8K which will go a long way to funding research for Meningitis and supporting families that have been affected. Donations are still being accepted until 30 June 2019.



**If you would like to support this invaluable cause please visit:**

<https://mydonate.bt.com/fundraisers/aisskydiveforayesha>



## CHANGES HERE AT AIS

Due to ever increasing numbers we now have a new surgeon on our team! We are delighted that Mr Marcel Geyer, an experienced ENT Surgeon, joined us in April 2019. He will be carrying out CI surgeries at Salisbury District Hospital and running clinics here at our centre in Southampton on Tuesday afternoons. As part of his

ENT training, Marcel spent a year working with pioneering cochlear implant surgeon Professor Bill Gibson in Sydney, Australia, performing many CI surgeries before returning to work in the UK.

You may know we were previously split into three teams based on the geographical

area in which you live. We will now have four teams; West, Central, East and North. Whilst this helps with continuity of care and patient management, we are ultimately still one big team and we all work our hardest to ensure the best service for you all.



# MORE PEOPLE ELIGIBLE FOR COCHLEAR IMPLANTS ON THE NHS

In March this year, many more people across all ages became eligible for NHS-funded cochlear implantation. The National Institute for Health and Care Excellence (NICE) has announced a change to the guidelines that will allow hundreds more people to receive cochlear implantation on the NHS. The new guidelines came after a long period of work by professionals and cochlear implant users to make sure that new evidence about who benefits from cochlear implants was considered by NICE. Information on the changes in the guidelines can be found at [www.nice.org.uk/guidance/ta566/chapter/1-Recommendations](http://www.nice.org.uk/guidance/ta566/chapter/1-Recommendations).

The changes are: people with hearing levels (without their hearing aids) equal to or poorer than 80 decibel (dB) rather than 90 dB can now be considered for NHS-funded cochlear implantation. Also, the new guidance applies at “any two frequencies” across a wider range so that people with different patterns of hearing loss across different frequencies can be considered. For adults, a different test of speech perception will be used to decide if they receive adequate benefit from their hearing aids - this is a word-based speech listening test rather than a sentence-based listening test. The change in the guidelines is fantastic news as it means more people than ever before will be able to benefit from cochlear implantation.



## CHOICE - COCHLEAR IMPLANT HOME CARE - AN ALTERNATIVE WAY TO LOOK AFTER YOUR HEARING!

The Auditory Implant Service is excited to provide an alternative care pathway- a home care pathway for patients who want to manage their cochlear implant care themselves at home. Currently, patients are seen in the department for an annual review or their hearing is monitored via long term questionnaires. The home care pathway involves using a personalised website (web app) called CHOICE where patients can do a hearing test at home, access music or telephone training, practise listening in background noise, request spares and access a general check-up questionnaire. Patients using the CHOICE care pathway can still come to the cochlear

implant centre when they need help with something.

**Currently the CHOICE care pathway will only be available for cochlear implant patients who have had their first annual review and are 18 years old or more.**

**Please note: CHOICE will not be suitable for all adult patients. If patients are following the CHOICE home care pathway then they will still be invited to attend the department for their third annual review and speech processor upgrade appointments.**

The CHOICE home care pathway registration is due to open in summer 2019. An information sheet about CHOICE and the registration information can be downloaded from our website [ais.southampton.ac.uk/patients-cochlear-implant](http://ais.southampton.ac.uk/patients-cochlear-implant) or email [AIS.choice@soton.ac.uk](mailto:AIS.choice@soton.ac.uk)

**CHOICE**  
COCHLEAR IMPLANT HOME CARE

# STAFF UPDATE

## HELLOS



### **Becky Parsons**

My name is Becky and I joined the team in January as a Clinic Support Assistant. You will see me on the reception desk and in the Spares and Repairs department. I previously worked at a busy NHS dental practice so am familiar with working in a clinical environment and helping patients. I am really enjoying my role so far. The team have been so friendly

and welcoming and I am thrilled to be part of USAIS. I look forward to meeting you all in the not too distant future.



### **Marcel Geyer**

We welcome Consultant Otolaryngologist Marcel Geyer to our team.

Marcel has previously worked as an Honorary Clinical Fellow for the Cochlear Implant Service and Advanced Otology Unit at the Royal Prince Alfred Hospital and Children's Hospital Westmead in Sydney, Australia. He will now share time between his new post

at AIS and his current role as a Consultant in Otolaryngology at Salisbury District Hospital.



### **Laura Merwood**

My name is Laura and I am a new Audiologist on the Central Team. I have worked as an Audiologist in the NHS for the last 10 years. I have been made to feel very welcome by everyone at USAIS since I started and I am looking forward to what this new role has in store.



### **Anna Read**

We would like to welcome Anna Read who will be working as Senior Administrator responsible for communication, events and the reception service. Anna has worked for the Evaluation Trials and Studies Co-ordinating Centre which undertakes research for the NHS, for the past year.

## GOODBYES



### **Amy Stephens**

We're saying "hasta la vista" to Amy Stephens this summer, after 13 years at AIS as a Speech and Language Therapist and Sensory Integration Specialist. Amy has an exciting opportunity to expand her role consulting and teaching in Ayres Sensory Integration, and to develop strategies to help cochlear implant services support children and adults with sensory integration challenges. This means that she won't be able to fit in a full time clinical role too, and so a new Speech and Language Therapist will be joining the AIS team to step into her shoes. Never fear though - you'll still see Amy around the clinic in Southampton where she will be helping out with appointments through the busy summer months, and we will still be accessing her advice and input on Sensory Integration.

## CHANGES TO OUR SPARES AND REPAIRS SERVICE

USAIS will be changing the way we provide our Spares and Repairs service to our cochlear implant patients over the coming months. We will be working closely with the implant companies to achieve this, improving the way you access help and advice when you have a problem with your equipment. These changes will guarantee a speedy delivery of equipment, in the correct size and colour, to the correct recipient, every time.

Initially these changes will only affect those USAIS patients who have an implant provided by the company Cochlear. USAIS will be

partnering with Cochlear and using their own 'direct to patient' service called Cochlear Care. Soon, we will be in touch to ask you whether you agree to share some of your information with Cochlear. If you agree, from then on Cochlear will deliver any items you require directly to your home, or wherever is most convenient for you.

USAIS will remain as your primary point of care and you can contact us at any time to discuss any concerns you may have. You will still see USAIS staff for appointments, and the USAIS Spares and Repairs team will still be here unchanged, allowing us to focus on

making sure that all of our patients receive the best possible service.

Similar services to Cochlear Care are provided by both Advanced Bionics and MED-EL for their implanted patients. USAIS is reviewing these services with the hope that we can start using them in the near future.

Should you have any concerns or queries regarding these changes then please feel free to get in touch at [ais.repairs@soton.ac.uk](mailto:ais.repairs@soton.ac.uk) or call on 02380 593522, and we will be happy to discuss it with you.

## USAIS GOVERNANCE BOARD – PATIENT AND PARENT/CARER REPRESENTATIVES NEEDED

The USAIS Governance Board meets twice a year for one and a half hours in the evening. Issues reviewed include patient and parent feedback, clinical and non-clinical audits, significant events, information governance and issues about the different cochlear implant manufacturers. Being involved in the Governance Board is an opportunity to help the Auditory Implant Service by contributing to its effective running and allowing input into the continued drive to improve standards for all patients.

Governance Board Meetings take place in May and November on a Wednesday from 5.30 -7pm in Building 19 – exact dates to be confirmed.



Please contact AIS Director, Carl Verschuur [C.A.Verschuur@soton.ac.uk](mailto:C.A.Verschuur@soton.ac.uk) if you are interested in being involved.

## SERVICE UPDATES

### HOW WOULD YOU LIKE TO RECEIVE THIS NEWSLETTER?

We are thinking about changing the way we send out service updates and patient stories (by email or on the website for example) – if you have any feedback we'd love to hear it! Email: [ais@soton.ac.uk](mailto:ais@soton.ac.uk)

### IMPORTANT

If you change your GP or other contacts for any reason it is essential that you let us know as soon as possible. If the GP on your record is not correct we may not be able to send you spares or arrange to see you.

### IS THERE SOMETHING YOU DON'T UNDERSTAND?

We're happy to help.

Contact us: [ais@soton.ac.uk](mailto:ais@soton.ac.uk)

## PARENTS – WE NEED YOU!

We are looking for parents/carers to be involved in shaping the service that we offer here at the USAIS. There is a meeting once a month – the next meetings are planned for 5 July and 2 August 2019 from 2.30 – 4pm.

If you are interested please get in touch with your child's key contact.

## UNSUBSCRIBE

If you would prefer not to receive this newsletter in future please just let us know and we will update your preferences.



## Contact us

[www.southampton.ac.uk/ais](http://www.southampton.ac.uk/ais)

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