

Newsletter

Issue 32 | Summer 2013 | University of Southampton Auditory Implant Service

SOECIC has a new name

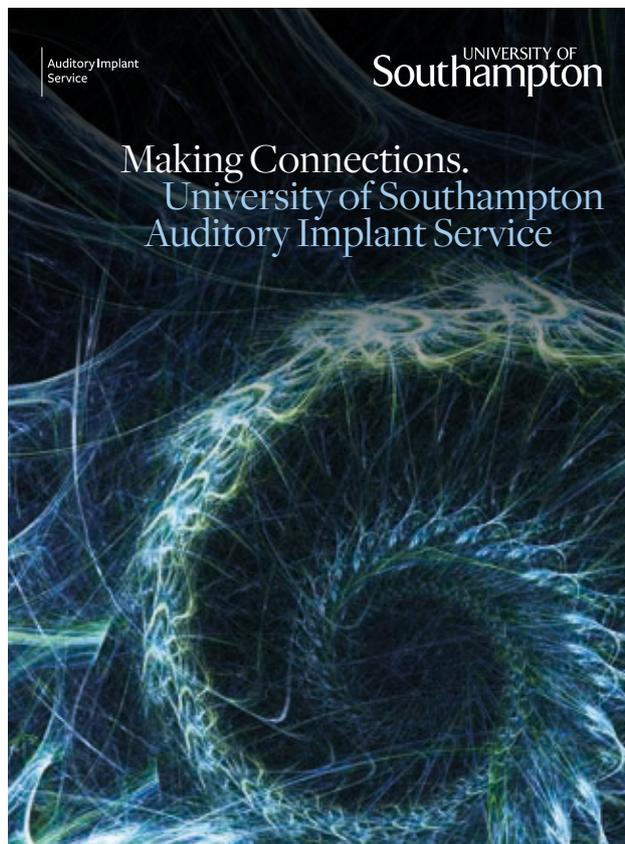
Most of you will know us as the South of England Cochlear Implant Centre. Twenty-three years after being established we decided it was time for a change.

Our new name is the University of Southampton Auditory Implant Service (USAIS). We have changed our name to reflect the fact that our work has expanded greatly since we were established in 1990.

Julie Brinton, Director of the service said "It is really pleasing to see how the centre has grown over the last 20 years or so. As a team we have learnt new skills in bone anchored hearing aids and other types of implants so we really want to move forward with all the new aspects of our work".

As well as a long established Cochlear Implant Programme, we now also offer services for Middle Ear Implants, Bone Anchored Hearing Aids and Auditory Processing Disorders.

We're still based in the same location and have no plans to move any time soon!



We have updated our literature to reflect our new name

Due to our name change we have updated our website and all of our leaflets which feature many of our own patients. If you haven't had a look already then visit www.southampton.ac.uk/ais

If you have any ideas about what you would like to see on the new website then we would love to hear from you so please get in touch.

Introducing our new services

We are now offering the following services in addition to Cochlear Implants

- Middle Ear Implants
- Bone Anchored Hearing Aids
- Auditory Processing Disorder Service

Middle ear implants are surgically implanted hearing aids which send a signal to the middle ear without the need for ear moulds. They can be suitable for people who have moderate to severe hearing loss and cannot use a hearing aid.

A bone-anchored hearing aid system (BAHA) is a device which converts sound waves into sound vibrations which are delivered directly to the inner ear through the skull bone. It uses the principle of bone conduction. BAHAs can be suitable for people who have a range of hearing losses that may be conductive, mixed or sensorineural.

An Auditory Processing Disorder (APD) refers to difficulty processing what is heard. APD is characterised by poor perception of speech and non-speech sounds, has its origin in impaired neural function and impacts on life through a reduced ability to listen. We offer a two level system, which allows for flexibility and is cost-effective. Level 1 entails a screening assessment and interdisciplinary guidelines for the individual, their parents/family and school/workplace. Level 2 offers a more in-depth assessment and management, if required.



We are now offering three new services

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.

Bilateral Conference Success

On the 11th of April 2013 the Auditory Implant Service hosted a conference to celebrate the results of an audit evaluating the outcomes of bilateral cochlear implantation for children.

It took place at the Turner Sims Concert Hall in Southampton and the feedback was overwhelmingly positive. Lots of comments were made about how useful it was to have a conference for both parents and professionals: a real chance to hear different perspectives.

As some of you may be aware, cochlear implants have been available in the UK for over 20 years. In 2009, a report by the National Institute for Health and Care Excellence (NICE) recommended that children receive bilateral cochlear implants (one for each ear).

Fifteen UK cochlear implant centres formed a consortium to evaluate the safety and multi-disciplinary outcomes for these children.

The papers presented at the conference reported the exciting findings from over 1000 children.

Results indicated that bilateral implantation for severely to profoundly deaf children is safe and helps them to achieve maximum benefit.



Jacob Collinson

Highlights of the day included a presentation from James Collinson, whose son Jacob received bilateral cochlear implants in 2011, and Jack Moodie, a seventeen year old cochlear implant user, who gave a rousing speech on what his implants mean to him.

Jack received his first implant in 2004 aged

8 before the NHS routinely funded two implants. He took the opportunity to have a second operation in 2012 aged seventeen and became a bilateral cochlear implant user.

Jack told the audience about the positive difference he has noticed since receiving the second implant, and the new noises he can now hear – like the quiet ticking of a clock!



Left to Right: Julie Brinton, Devyane Bele and Helen Cullington from USAIS all presented results at the conference

Teens' Event at Sector 7 Laser

We had a great time at Sector 7 Laser in Southampton on 16th March 2013. Seventeen teenagers with cochlear implants attended, many travelling long distances to be there.

It was lovely to see so many familiar faces and to welcome others who were new to the teens programme. Several of the teenagers were already familiar with laser quest but it was new to a few and certainly new to most of the USAIS staff.

Before we started the games there was a chance for everyone to get to know each other a bit and for the teenagers to be split into two teams. We were given instructions on what to do. It sounded complicated: the lights on the gun flashed and changed colour according to whether you had been 'shot' or if the gun needed re-charging, and once you had been shot the gun would not work for a while. Luckily, once we started to play it all seemed to make sense.

We had a few minutes to run around to work out the layout of the arena but then the lights went off and it all went dark! The arena was dimly lit so that you could only just see your way around. Some teens hid in corners, others went in for the attack!

There was definitely some skill involved but it was good fun for novices and experienced players alike. We had a break in the middle and a chance to check the scores. Once the second game had finished and the winners were announced (well done Jarvis and Henry!) we took a well earned rest and had our lunch all together sitting at the tables. The food was hot and tasty and didn't take long to demolish! It was great to see the teenagers chatting to each other – certainly some friendships blossomed that day.

The teenagers filled in some feedback sheets at the end of the event. Overall, I think everyone enjoyed it, here are a few of the comments that were made; '(I liked it) because it was awesome and fun', 'good new funny friends and fun game and I'm good so I had fun myself' and 'this was my first time and it was amazing'.



We had a great time at Sector 7 Laser

Patient News

Stuart Ring has written to tell us of his Thomas Hardy School Academic 'Black Tie' Award



Stuart Ring has received an academic award

"My name is Stuart Ring and I am 15 years old. I was 2 years old when I had my cochlear implant. I go to The Thomas Hardy School in Dorchester and I am in Year 10. My favourite subjects are games and science. My best science subject is physics. My favourite sports are swimming, golf, gym and free running. For fun, I like to work out how much power and strength I have, for example, how fast I can run and how much I can lift.

At Christmas I was awarded an 'Academic Black Tie' for science. I got the award because I had achieved two high grades for physics and chemistry. In the assessment exams I got top marks in my science group. Academic Black Ties can be given for any subject, for example, history or maths.

There are different types of ties for academic achievement, sport participation or

community involvement. The Black Ties are a reward for excellent personal achievement at any level in these areas.

There are 6 deaf students at my school and 4 of us have got black ties for different achievements! This shows that deaf students can do anything...never give up! I want people to know that deaf students can achieve something...we are equal to hearing students; we are only different because we can't hear.

I work really hard and I want to be a science teacher in the future, hopefully at a school for deaf children. I am working really hard and I never give up! I study all the time because I want to get into the sixth form and then university. If I went to university I would study science and sport."

Team Immy recently raised funds for a meningitis charity GBSS.

Immy's mum wrote:

"Imogen was born 6 weeks prematurely on the 20th February 2012. Shortly after her due date, on the 8th April 2012, our world was shaken beyond belief. That morning we took Imogen to hospital to see an out of hours GP as it was Easter Sunday. It turned out to be the best decision we ever made as on arrival, our baby who just didn't seem to be quite right, went drastically down hill. Imogen was rushed into A&E and placed on a ventilator. She was pumped full of a broad spectrum of antibiotics and later transferred to the John Radcliffe Paediatric Intensive Care Unit.

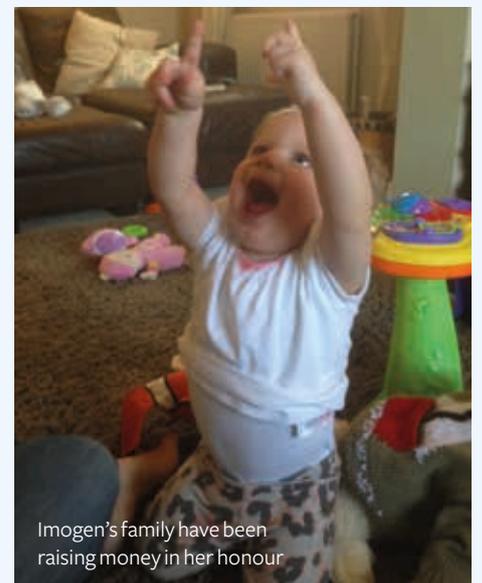
The following day she was given a lumbar puncture just to rule out meningitis. When the results came back as positive our world fell apart. Imogen we knew was profoundly deaf at birth, what else could she lose now she had this dreadful disease? Late onset Group B Strep (GBS) infection had overwhelmed her body and led to meningitis. She was only 7lbs, and her tiny body had to fight GBS meningitis and septicaemia. We knew that she faced a very uncertain outcome and that we could lose our precious baby girl.

Amazingly, due to expert care she received at both the Royal Berkshire & John Radcliffe hospital, our miracle baby slowly recovered. I'm over the moon to say she went on to make a full recovery. She is now almost a year old and is reaching all her developmental milestones and can hear with cochlear implants. We are the luckiest people on the planet, but things could so easily have gone the other way.

By running the Reading ½ marathon we hoped to raise awareness so that far fewer people have to experience the pain and anguish we did. We hope that all women will be offered accurate and reliable GBS testing & information as part of their routine antenatal care in the future, along with antibiotics in labour if required to prevent early onset infection. The ultimate goal is that a vaccine can be developed to eradicate this terrible disease, as this would prevent both early and late onset infection. Funding is required to enable this to become a reality.

To date we have raised £1,960 & are over the moon with this achievement. Both myself & my husband found running the ½ marathon

for GBSS quite an emotional journey on the day itself. Imogen's face was very much in the forefront of our minds and just how lucky we are to have her. I know the thought of helping other families kept all of Team Immy running on the 17th March 2013, through the freezing rain & cold."



Imogen's family have been raising money in her honour

Jo Deacon has written to us about her own experience of having a cochlear implant. A full version of her story is on our website.

Here is a taster of her story:

“October 2013 will mark the third anniversary of my cochlear implant. Even now I’m still hearing new sounds and my understanding and speech recognition is improving every day. I still can’t believe how lucky I am and if there’s one thing I regret it was that I didn’t have it done sooner! I guess having the cochlear implant isn’t for everyone and is a personal choice but I have to say I’m a huge advocate for it and tell everyone I know that I have one and the huge benefits I’ve had.....

I met my consultant in June 2010 and two audiologists who between them carried out numerous tests. I then had scans in August. I was offered some ear defenders which I declined because I couldn’t hear a thing anyway! The expectations counselling made me think about my choice to have a cochlear implant and the impact of the procedure. I had long hair, and naturally being a woman I

was worried about having some of my lovely hair shaved off. Looking back, it really wasn’t noticeable at all.

The big switch on was 8 weeks later. I took my closest family and friends including my two children to some of the tuning appointments so they too could feel involved and it was lovely to share those moments with them. On a very personal note, the one person who has been there constantly throughout all of my journey is my husband Paul. On my worse days he was there to pick me up and give me the positivity I needed and on my best days he was there to share the new and great things.

After spending years living with the best hearing aids the NHS could offer at the time, the cochlear implant is a totally different world of sounds. Birds are noisy, children are louder than I remember and not being able to find the origin of some sounds drives me nutty as I can hear them but can’t see

them! As a childminder I work with children everyday and the quality of the sounds after the implant made such an amazing difference. Being able to hear them make sounds of dinosaurs roaring and the delight of hearing them screaming and laughing when they play is an absolute joy. I’m able to use the telephone with people I know. I’ve been told my speech is clearer but I’m quieter. No more whistling from those NHS hearing aids and no being told I’m shouting.

I turned 40 last January and decided to have all my lovely long hair cut off! All that worry pre op about losing my hair. So turning 40, a new hairdo and the ongoing learning, the implant was really doing its job. To all those that are thinking about having a cochlear implant, making the first move is the beginning of the rest of your life. To sum it all up, I don’t regret it. I’m very grateful to be able to have had the implant fitted.”

Lisa Baldock told us about why she abseiled for charity.

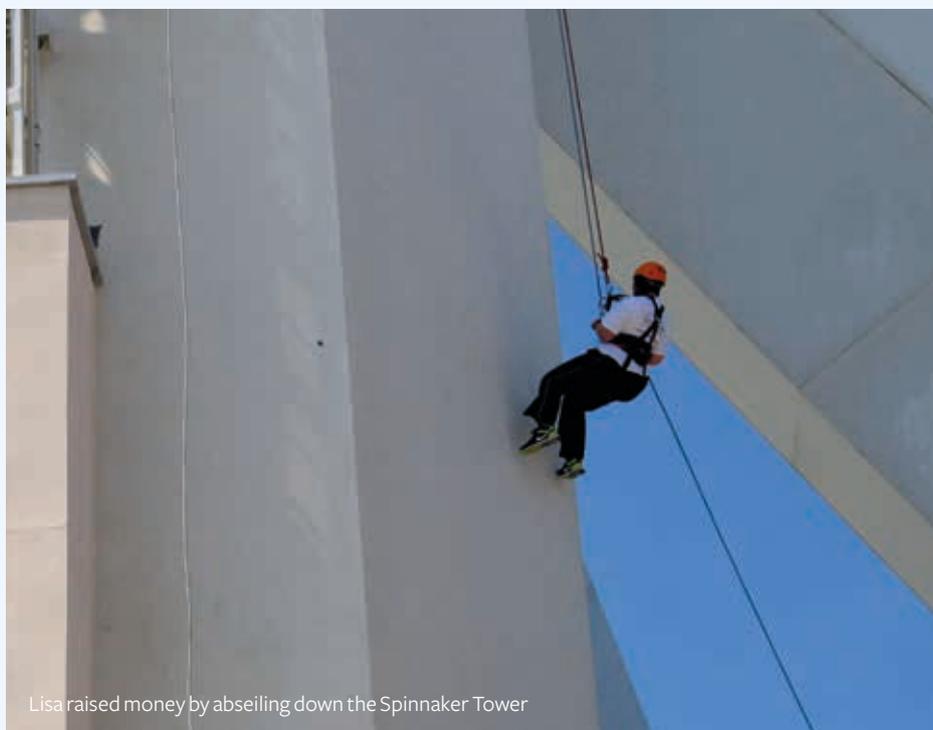
In April 2012 I was matched to my hearing dog Inca. I’ve waited 5 years for her and although I was implanted in 2011 I still found I needed support in my life.

Inca’s changed my life. She helps me with sounds I don’t hear or recognise, gives me confidence to get out and also helps me with my depression.

On May 26th this year I set myself a challenge. To do an abseil of the Spinnaker Tower in Portsmouth. I hate heights but I wanted to give something back to the charity who helped me and face my fears. 10 friends joined me. Inca watched me with her friends too.



Lisa Baldock and Inca



Lisa raised money by abseiling down the Spinnaker Tower

So far I’ve raised over £1000 but the total of the day looks set to raise over £5000. This money will help to train other hearing dogs and also reduce the 5 year waiting list.

How do I feel now? I feel elated. Life seems to be getting better since the day I was

implanted and also Inca completes it. Just goes to show you can still maintain a normal life after implantation ! Inca sends you all woofs.

Forthcoming events

Auditory Implant Service Patient Event

We are holding a summer fete on Saturday 14th September 2013 at the University of Southampton. There will be lots of fun activities for all ages including a fire engine, tombola and face painting. All patients, friends and family are welcome. Please fill out and return the attached invitation slip to R.S.V.P.



We are planning a WaterWalkerz event for teenagers

WaterWalkerz

By popular demand we are inviting all of our teenage implant users (13-18) to WaterWalkerz in Southampton in April/March 2014. It looks like brilliant fun – more details will be available in the next newsletter.

Teenagers, Telephones and Technology, Try IT and Test IT Day

We will be running this day, free of charge, on Saturday 19th October 2013. The day is aimed at those teenagers who are able to understand some speech without lip reading. Please contact Rebecca Ricaud at R.A.Ricaud@soton.ac.uk if you are interested in either or both of the teen events.

Deaf World

[Sonus] are hosting their annual Deaf World event on Friday the 27th September 2013 at Southampton Guildhall. The event is open to everyone and entry is free. No booking is required just turn up between 10am and 4pm. Members of staff from the Auditory Implant Service will be attending so it will be a chance to catch up with us too!



Sir Cliff Richard has given access to his music to support a University project

Photo credit: Alan Olley

Sir Cliff Richard supports Southampton music project for CI users

Members of the Music Focus Group at Southampton are currently busy working on a number of activities as part of the 'Compositions for Cochlear Implantees' project. We are improving the 'Interactive Music Awareness Programme' (IMAP) that was trialled here last year by USAIS patients. The IMAP is a computer software programme that can make music more accessible and fun for cochlear implant users.

At the end of the project the programme will be launched online so that all cochlear implant and hearing aid users will be able to benefit from it for free. The Arts and Humanities Research Council has provided the funding to make this possible.

As part of the improvements to the resource we have been approaching artists to ask them to provide music for us to use. We are absolutely delighted to announce that Sir Cliff Richard has given us access to the individual instrumental and vocal tracks from his number one hit We Don't Talk Anymore. Other exciting artists are to be announced soon and the resource will be online from January 2014 at <http://morefrommusic.org/>

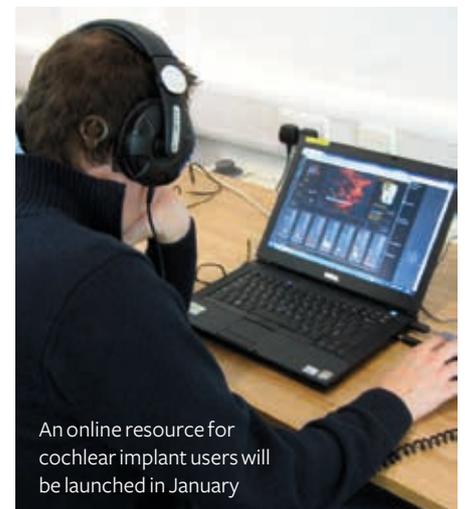
Part of the project also involves developing music workshops for cochlear implant users and for professionals who want to know more about how to run successful workshops. On Friday 13th September we will be hosting a workshop for professionals such as audiologists, music, hearing, speech and language therapists and community

musicians. Our aim is to highlight the benefits of music workshops for cochlear implant users and to help professionals feel confident and equipped to provide workshops in their own settings.

This event will be closely followed by a music workshop for cochlear implant users at the Auditory Implant Service on Saturday 14th September. If you are interested in learning more about listening to music through a cochlear implant and would like to try out the latest version of the IMAP then please contact Mary Grasmeder (mlf4@soton.ac.uk) or keep an eye out for more information on our websites:

www.southampton.ac.uk/mfg/current_projects/compositions.html

<http://morefrommusic.org/>



An online resource for cochlear implant users will be launched in January

Technology Update



Advanced Bionics TComm

The T-Comm is a lightweight accessory that can be attached to the Neptune processor via the headpiece lead which allows Neptune (or PSP) users to wear a T-mic on the ear. Tmics have previously only been available to Harmony speech processor users. The T-Comm also features a built-in T-Coil for wireless access to loop systems.

We will be offering the T-Comm to adults who have a Neptune speech processor. We will not offer the TComm to adults who have both a Neptune and a Harmony processor as they already have access to the telecoil and T-mic, unless there is a clinical need.

We will also offer the T-Comm to children with Neptune processors who need to use a neckloop to use their radio-aid/s. It will be available on request to children who wish to use a loop system or telecoil.

Talk to your audiologist at your next appointment if you are interested in the T-Comm.



Cochlear Aqua Accessory

Cochlear has brought out the 'Cochlear Nucleus Aqua Accessory' which is suitable for use with CP810 (N5) speech processors.

It can be used in all types of water – such as chlorinated swimming pools, sea water, or soapy baths. It is a plastic enclosure that completely seals in the speech processor, cable and coil.

It is made out of clear flexible plastic so that you can access the control buttons and reposition the coil. It is designed for use with rechargeable batteries only.

The Aqua Accessory can float, which makes it easy to recover in a pool or bath if dislodged and there is a hole for a safety line if needed. It has a quick tear notch for easy removal and is designed for single use only.

They can be purchased from Connevans - the current price is £32.40 (ex VAT) for a pack of 30.

Reminders

You can now email
Repairs directly:
ais.repairs@soton.ac.uk

Ladies – if you have you been called to have a mammogram read on

After going for a routine mammogram, one of our patients commented that it would have been helpful to have something to give to the staff to explain what a cochlear implant is and some of the safety guidelines as recommended by BCIG. Full safety guidelines can be found at www.bcig.org.uk/site/public/current/safety.htm

The University of Southampton Auditory Implant Service can now offer support in the form of a letter to take with you when you have a mammogram.

This letter states that you have a cochlear implant. It briefly describes what a cochlear implant is and how it helps the implant user. It confirms that you need to remove and switch off the speech processor prior to the procedure, and keep it well away from the x-ray equipment. The letter requests that the person doing the mammogram explains the procedure and what you will need to do before taking off your speech processor.

If you are called for a mammogram and would like a letter to take with you please get in touch and we will send a letter to you.

Holiday Loaners:

If you are planning on taking a Holiday Loaner processor away with you on your travels this summer please remember to get your application forms into your respective manufacturer as early as possible and no later than two weeks prior to travel. This helps us ensure that you will be able to receive your equipment in good time before you travel. If you have any questions regarding this scheme then please don't hesitate to get in touch via phone or email.

Have you visited our new website?

To keep up to date in between newsletters visit our new website:

www.southampton.ac.uk/ais

There is a wealth of information to discover including:

- Resources for teenagers
- Communication tips for parents
- A guide to Personal FM Systems
- Research articles
- Updates from our service
- Details of social events



Hello and Goodbyes!



I still remember the first day I arrived at USAIS (SOECIC at that time) as an Erasmus student. I was welcomed by a team of great people and I was impressed by the

centre, the work and last but not least the patients. From that day onwards I knew I wanted to work with cochlear implants.

I returned last summer to cover Sarah B's maternity leave and I can honestly say this year has been amazing. The best first job a girl could wish for!

This summer I will start working as a clinical specialist for one of the cochlear implant companies and I will be responsible for South Africa, Israel, Iran and Eastern Europe. I want to say a BIG thank you to all of my colleagues and all the patients I have met here. Thank you all for this unforgettable and priceless experience!
– Ellen Joos



Hi, my name is Steve Bell and I've been working as an Audiologist here for the last year. I won't be conducting clinical sessions at the centre from July as I will be

concentrating on teaching with the Hearing and Balance Centre next year. There will be a heavy teaching load due to a double final year of audiologists.

I will miss working with the lovely patients and staff at the centre, but I'll still be involved in a number of research projects related to cochlear implants and in work on developing new clinical test procedures using evoked responses with implants.



Welcome back to Helen Lakeman (left) and Sarah Baumann (right) who have both recently returned to work following maternity leave. Congratulations to them both on the birth of their babies.



Hello – I am Shirley Effamy and I started working here at USAIS as a Clinic Support Assistant/ Receptionist in March. I previously

worked as a PA to the Sabbatical Officers in the Students' Union here. I am really enjoying the face to face contact with the patients and being part of a great team that makes a difference to people's lives.



Hi, I'm Katherine Vowles and I joined the team in February as Admin and Training Support Assistant. I previously worked for

Southampton City Council in disabled children's services.

As part of my new role I will be assisting the BAHA, APD and Middle Ear patients. I am really enjoying being part of such a diverse team and I look forward to getting to know many of you in the future.



Melanie Jewett is training hard for the Deaflympics

An Update from Melanie Jewett

One of our cochlear implant patients, Melanie, tells us she is training hard for her marathon at this Summer's Deaflympics and is now also competing in the 10,000m on track.

Her training currently involves high mileage of around 65-70 miles a week and includes a variety of different training sessions including track, hill work and very long runs. It is proving to be tiring and hard work, especially fitting it around her full time job and life in general, but this is a once in a lifetime opportunity and she has never been more motivated.

As well as the training, Mel has been working hard at fundraising too. The marathon has been moved to Germany, while the 10,000m takes part with the rest of the Games in Bulgaria. Therefore, she needs to raise more than the original £3,500 originally set to get to Bulgaria.

Good luck Melanie.

Thank you from Guoping

I have raised £375.00 for Destiny of a Child & the Ear Foundation. Thanks for everyone's generous donations! Guoping

Contact us

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

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