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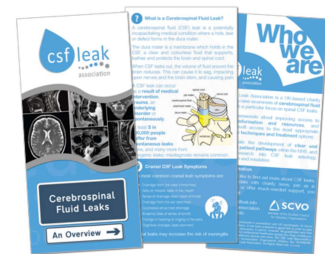
Message from the Membership Secretary

Hello, <<First Name>>. Welcome to the third edition of Leaker Life. In this edition, aside from being jam-packed with articles and information, we are thrilled to announce that we will be opening for membership in January 2017!

Since setting up the charity at the beginning of this year, we have been working hard behind the scenes to prepare all the necessary documentation and resources to enable supporters of the charity to become members. More information about the benefits that membership brings can be found at www.csfleak.info/membership

Included in each membership pack will be several copies of our new leaflet 'Cerebrospinal Fluid Leaks: An Overview', which can be used as a reference point for patients or can be given to relatives and friends who might want to know more about the condition. The leaflet has been produced with the kind assistance of UK neurologists, Dr. Simon Ellis and Dr. Manjit Matharu. A PDF version is also available via our website.

Of our other exciting ongoing projects, work is



Cerebrospinal fluid leaks: an overview

The newest addition to [our factsheet and leaflets](#) series - *Cerebrospinal Fluid Leaks: An Overview* - was published in November 2016 and is available now to download via our website.

Produced in consultation with UK neurologists, Dr Simon Ellis and Dr Manjit Matharu, the leaflet covers a range of key facts about CSF leaks, as well as common symptoms, diagnosis and treatment.

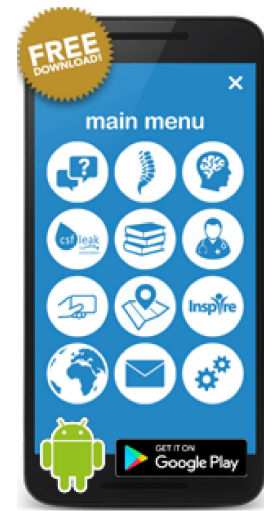
The leaflet is ideal for downloading, printing off and taking with you when you visit your doctor. [Learn more](#)

progressing well on our Medical Advisory Board front. We are currently working with several leading medics here in the UK to get the body off the ground and will be making more announcements in 2017.

We are working with a number of doctors to review, update and supplement our existing factsheet series, and other publications and resources. We also hope to be working with them to arrange the authorship and publication of medical papers for publication in medical journals and to develop pathways through which patients can be treated within the NHS.

May I take this opportunity to wish you all a very happy and peaceful Christmas!

Sarah Mead
Membership Secretary



If you've got an android mobile phone or tablet, why not download our brand new CSF Leaker Companion app?

[Find out more](#)



Diskogenic microspurs as a major cause of intractable spontaneous intracranial hypotension.

This new paper, produced recently by experts in Switzerland, details a case study of 69 consecutive patients between Feb 2013 and July 2015, 15 of whom presented with intractable symptoms.

Imaging revealed a suspicious single leak location. 14 progressed with microsurgical exploration. In 71% of those patients, a ventral, calcified microspur originating from the intervertebral disk perforated the dura like a

knife. The microspurs were removed and dural slits sutured with immediate cessation of CSF leakage.

It was concluded that an extradural pathology, diskogenic microspurs, was the single most common cause for ventral CSF leaks, challenging the notion that CSF leaks in SIH are idiopathic or due to a weak dura.

View the article on PubMed: www.ncbi.nlm.nih.gov/pubmed/27566748

Journal Article Library

We excited to announce that December 2016 sees the launch of our overhauled journal article library.

The database underpinning the library is built around the PubMed system, a respected biomedical literature database comprising more than 26 million citations.

Abstracts are provided for most articles and users can view more information on an article by clicking on a 'view article' link (where available). New publications are monitored and articles added are regularly.

Our favourite articles and articles that are likely to be of particular relevance to those with an interest in CSF leaks, as well as articles that we consider to be 'must-read', are all flagged for ease of reference. You can also search for articles in the database using titles, keywords or author names.

You can access the library here: www.csfleak.info/journal-articles



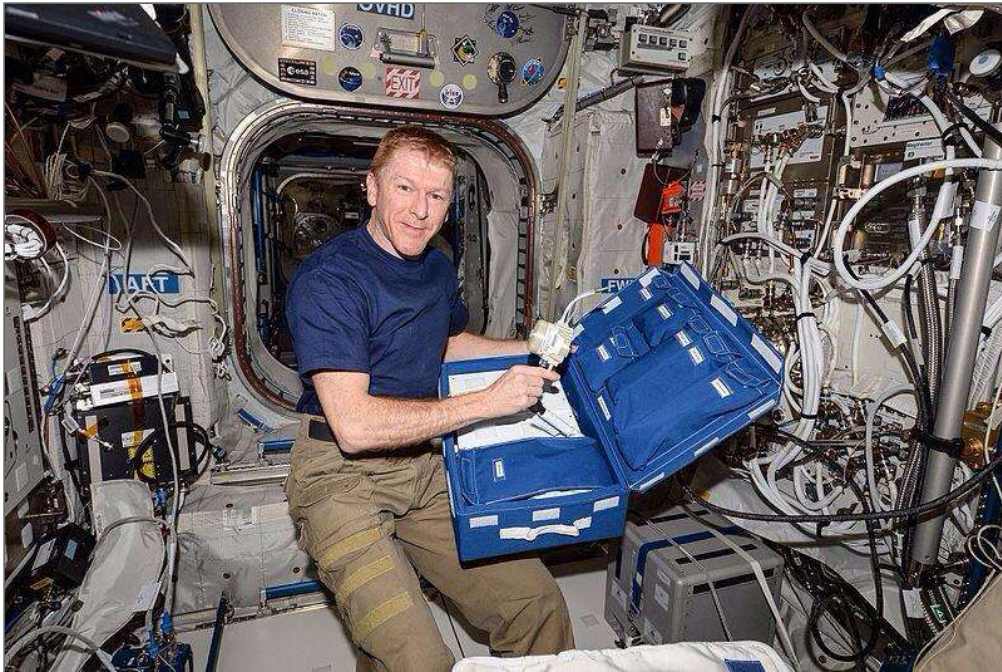
Intracranial Pressure Monitoring using non-invasive technique.

Our Trustee, Sarah Mead, talks to Dr Robert Marchbanks about non-invasive intracranial pressure monitoring.

On 15th December 2015, British astronaut Tim Peake started a six month space mission as part of the crew on board the International Space Station (ISS). Amongst the myriad of technical equipment that he took with him was a Cerebral and Cochlear Fluid Pressure (CCFP) analyser, which measures

Intracranial Pressure (ICP) using a method known as Tympanic Membrane Displacement (TMD). The CCFP, brainchild of Dr. Robert Marchbanks consultant clinical scientist at Southampton General Hospital in the UK, is the first piece of non-invasive equipment capable of monitoring ICP.

Having realised that astronauts commonly suffer fluctuations in intracranial pressure (high pressure can be a particular concern, leading to what has become known as Visual Impairment Intracranial Pressure (VIIP) syndrome) NASA and the European Space Agency worked alongside Dr. Marchbanks to include the CCFP as part of the equipment on the ISS so that an astronaut could use it in space to monitor their own intracranial pressure. On 6th May 2016, Tim Peake used the CCFP on board the ISS.



Tim Peake unpacking the CCFP on board the International Space Station.

This same piece of equipment has the potential to be used in hospitals worldwide to measure ICP without using the usual, invasive methods of using either a bolt screwed into the skull under general anaesthetic or by performing a lumbar puncture.



The CCFP in use

I was fortunate enough to get the opportunity to ask Dr. Marchbanks some questions about the CCFP on behalf of the CSF Leaks Association and am very pleased to be able to share his answers here.

(SM) How does the efficacy of the MMS-11 compare with the standard form of intracranial pressure (ICP) monitoring using a bolt screwed into the skull and resting on the meninges?

(RM) At the current time we are unable to provide an absolute measure of intracranial pressure, that is we cannot give an actual value for the pressure. We are able perform a screening test to ascertain whether the pressure is likely to be low, high or normal pressure. Perhaps more important in the case of CSF leaks, we are able to track pressure changes in an individual person and say if the pressure is likely to be the same, higher or lower.

Although we have seen patients with low pressure and have detected this, we have not specifically researched a group of patients who suffer from CSF leaks. We would need to do this to establish the efficacy of the Southampton CCFP (Cerebral and Cochlear Fluid Pressure) Analyser in this specific group of patients. Without a trial we would not know the likelihood of false-positive or false negative results, i.e. people we diagnose with a leak but are normal or people we diagnose as being normal but have a leak.

The technique is referred to as the 'Cerebral and Cochlear Fluid Pressure (CCFP) Analyser' and also the 'Tympanic membrane Displacement (TMD) Analyser', since measurements are made by detecting small movement of the tympanic membrane, i.e. ear drum.

(SM) I have read your paper on 'The tympanic membrane displacement analyser for monitoring intracranial pressure in children', has the MMS-11 been tested on adult patients that have known problems with low/high intracranial pressure?

(RM) We have researched children and adults who have a cerebrospinal shunt to control hydrocephalus. These can become blocked with the risk of high pressure or they can be too effective and the intracranial pressure become too low. The symptoms of both are similar and include headaches, so it good to have a means of differentiating one condition from the other. We have published a number of papers on this including:-

- Moss SM, Marchbanks RJ, Burge DM. Long term assessment of intracranial pressure using the Tympanic Membrane Displacement Measurement Technique. *European Journal Paediatric Surgery Supp I* 1991; 25-26.
- Samuel M, Marchbanks RJ, Burge DM. Quantitative assessment of intracranial pressure by the Tympanic Membrane Displacement Audiometric Technique in children with shunted hydrocephalus. *European Journal Pediatric Surgery* 1998; 8: 1-9.
- Samuel M, Marchbanks RJ and Burge DM. Tympanic membrane displacement test in regular assessment in eight children with shunted hydrocephalus. *Journal Neurosurg* 1998; 88: 983-995.



Dr Robert Marchbanks

(SM) The TMD technique is being used in a KEMRI (Kenya Medical Research Institute), has it been used by the NHS yet and if not do you know of any plans to do so?

(RM) The CCFP Analyser is CE-Marked for clinical use in Europe and elsewhere. It is used clinically in the NHS mostly at Southampton and for children in a London Hospital. It is not used extensively, and before this happens then we need to establish what is normal and the efficacy of the device. This work is underway in Southampton where we are collecting data from 360 normal adult volunteers. This work is being funded by Innovate UK. It is also being used on the International Space Station by NASA in collaboration with other Space Agencies. They need to establish how the intracranial pressure changes in space.

(SM) What training is involved for medical professionals using the equipment and those interpreting the results?

(RM) A medical professional can be trained to use the CCFP Analyser in a day, however, it takes a while before they have the confidence to interpret the test results. One of the main objectives of the Southampton work is to make testing easier both in terms of operation and interpreting findings.

(SM) Are there plans to share the results from the testing with UK doctors?

(RM) We wish to encourage UK and doctors worldwide to use the CCFP Technique. We are pleased to give advice to help set up clinical trials, and to support in any way we can. The Southampton reference data from the 360 normal adults will be available to medical professionals who need this for clinical use or medical research.

Sarah Mead (Trustee)
Autumn 2016

NB. If there are any further questions you would like us to put to Dr. Marchbanks on your behalf, please send them to: sarah@csfleak.info



We're about to open for membership: get ready to join us!

We are delighted to announce that the CSF Leak Association will open for membership at the beginning of January 2017.

Membership will be open to anybody aged 16 or over, irrespective of where you live. If you're under 16, you can still get involved through Junior Supporter status.

As well as supporting our work and helping to raise the profile of CSF leaks, membership will bring with it a number of benefits, including access to:

- A membership pack containing key resources and information
- The member-only section of our website
- Our membership mailing list, featuring regular updates
- Our members network directory

Membership also will also entitle you to attend members-only events, attend and vote at members' meetings, and provides priority access to tickets for information days, where medics from around the UK (and, we hope, further afield) will speak about CSF leak related issues.

Such events will also allow those of you able to attend the chance to meet other leakers and speak to trustees about the work of the charity.



There will be four types of membership to choose from:

- Individual (over 18) - *£15.00 per year*
- Individual (ages 16-17) - *£5.00 per year*
- Family (a family group living at one address) - *£30.00 per year*
- Incorporated/Unincorporated organisations - *£50 per year*

Junior Supporter will also be available to those under the age of 16 at £5.00 per year. Junior supporter will not be able to vote or stand for election, but will enjoy all other benefits of membership.

We'll be sending around a notification at the turn of the year - only a couple of weeks away - when membership officially opens to all, so keep your eyes peeled!



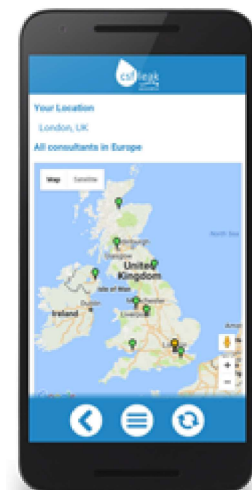
Calling all Android Mobile Phone and Tablet owners!

We are delighted to announce the release of our brand new Android app for CSF leakers. It's absolutely free and available to [download from the Google Play store](#).

The app provides easy access to key information and resources about CSF leaks, all at the click of a button or tap on a screen!

You can access information about cranial and spinal CSF leaks, and view a list of must-read medical journal articles, all off-line; ideal for use during an appointment with your doctor or when explaining things to friends and family.

View our global map of CSF leakers and add/edit a pin for yourself, search for doctors with some CSF leak experience near you (aimed at EU residents), or bring up a copy of our medical accommodations cards whenever you need it.



The app is brand new and is being updated regularly with new content, so please make sure that you select its 'auto update content' setting. If you have any ideas or suggestions for the app, please drop us a line.

To get a copy of the app, search for 'CSF Leak' in the Google Play app store, or point your device's browser to: www.tinyurl.com/csfleakapp

NB. If you already have a map pin on our Global CSF Leaker Map, please go to the pin, make a note of the number in the pop-up window (e.g. #250) and email

us at webmaster@csfleak.info with your Android account email address; this will enable us to link your pin with your CSF Leak Companion App.



In each issue, we hand the mic over to a CSF leak sufferer and give them the opportunity talk about anything leak-related. This time, it's Ingrid Snyder's turn...

Name: Ingrid Snyder

Age: 50

Home town: Cornwall, Ontario, Canada

Leak since: March 2016

Never in a million years did I imagine that a person could have a headache for longer than a couple of days, let alone 8 months...and longer!

When I woke up in the wee hours of the morning on March 19 of this year, I had no idea that this would mean a complete turn around of every aspect of my life, as I know it! It was going to mean a completely new frame of reference even though the awareness only came into my consciousness one day at a time.

Days turned into weeks, weeks turned into months, and so it went...mind-splitting headache when I sit up, nausea, vomiting, dizziness, ear and throat pain, desperation and debilitating pain with no refuge.

I, like many with CSF leaks, am allergic to many medications, so this complicates my treatment. I am unable to take most, if not all, pain medication, so I am limited to trying to control symptoms by accommodating my actions. I stay indoors, I lay in bed most of every day, I have to limit computer screen time, and I am sensitive to light and sound.

Throughout this illness, I have managed to make the best of things as much as possible. I can research about an hour or more a day as long as I am lying in bed. I use this time to plan my care and to inform myself for appointments and meeting with doctors.

I connect with other CSF leak patients through Inspire, Facebook, and The Mighty so that I don't feel desperate about not knowing what tests to order, what doctors to see, and just connecting with others who understand my limitations.

I have been sick throughout Spring, Summer, and now Fall which means that I am able to go out into my garden almost every day to get my mind clear and off of my own situation. I play with my dogs, or admire flowers, I have been known to do a little weeding although honestly...bending over is agonizing!

I call friends, I text family and friends when I need a boost and I fill my day by doing things that make me happy: I write letters, I blog, I crochet, I meditate, I listen to music or audio books from the library, I make crafts, I take pictures, I watch TV or TedTalks...really, I do anything to occupy my mind as long as it is not loud and not bright as this increases the headache.



I am still trying to find the right imaging in order to locate my CSF leak. This is a situation that is common to many with this illness. I keep in mind that when I first started teaching I did not know right away when I was teaching a student with a learning difficulty or a speech challenge as I got more and more experience, I got better at identifying certain markers in children that makes it much easier to pinpoint now that I have been teaching for many years.

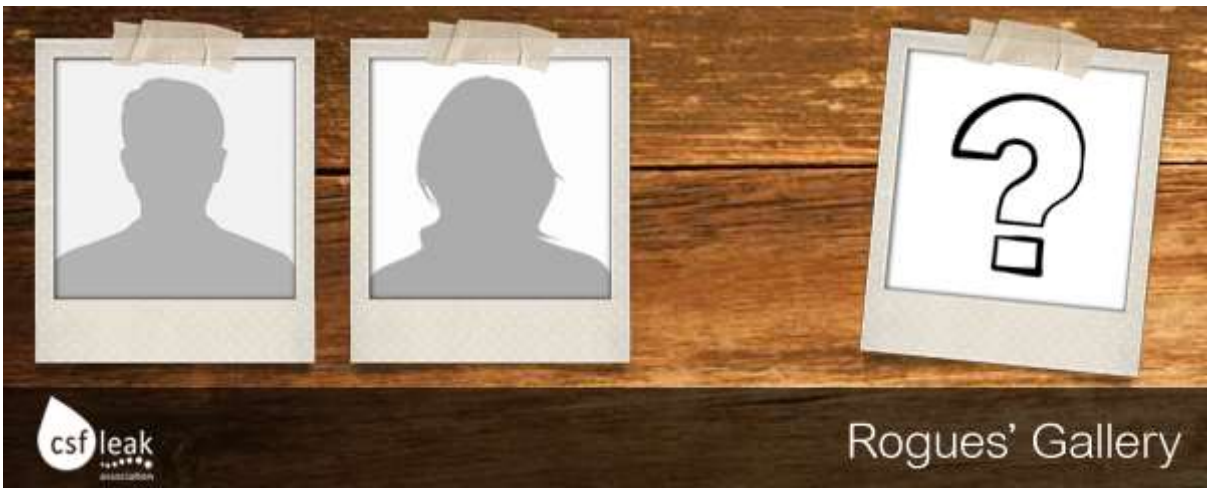
Similarly, doctors are not aware of the prevalence of CSF leaks and the trademark symptoms that are associated with this illness. It has been frustrating at times and it seems like a tremendous uphill battle but I really believe that the more often we can bring awareness to our issue the more widespread the knowledge of the medical world will mean this illness will be easier to diagnose.

I have had a number of diagnostic imaging tests done to try to locate my CSF leak and so far, doctors have not been successful. I know I am in good hands as my doctor is always ready to hear the next line of attack and is open-minded and accommodating.

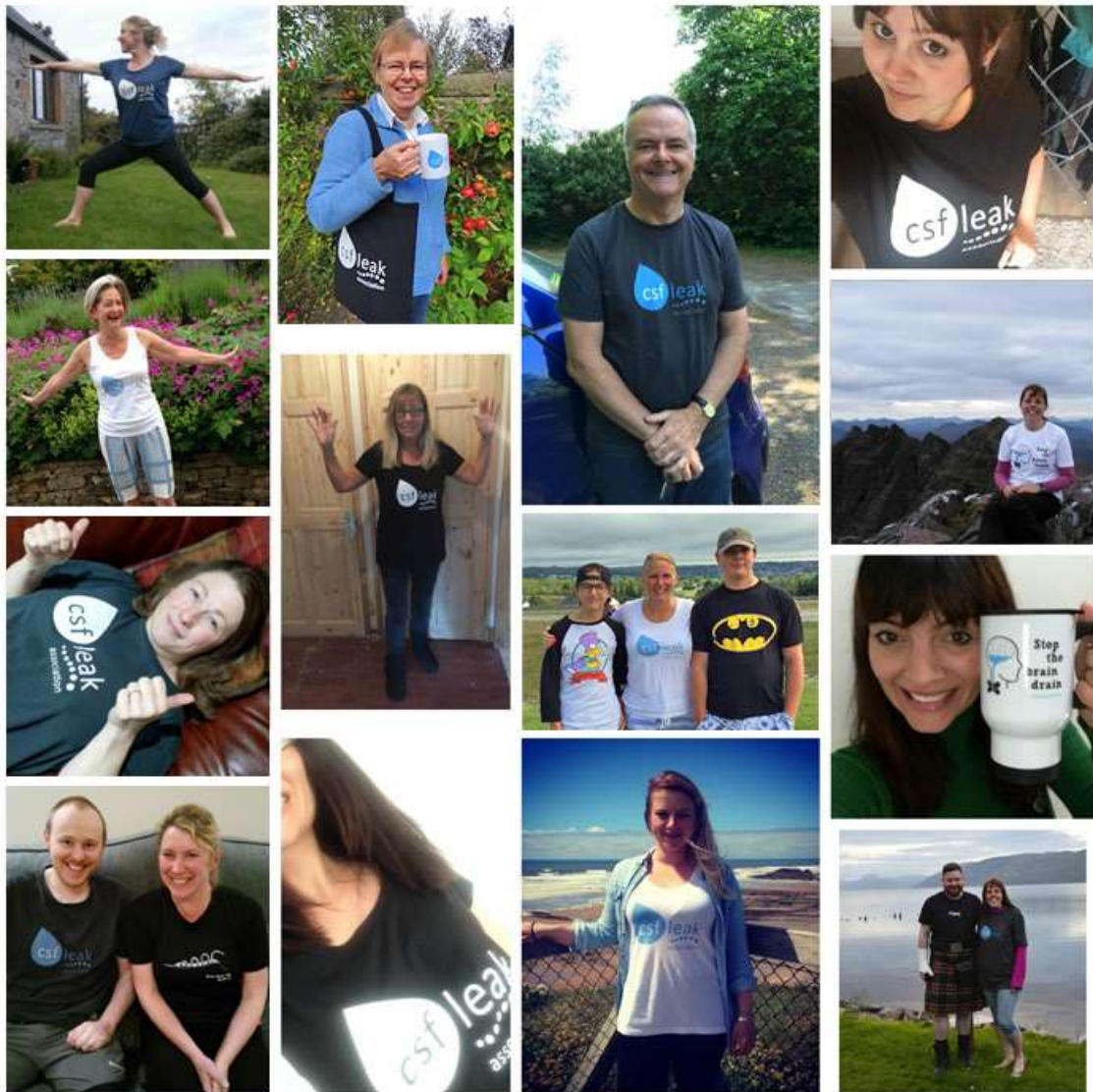
I know we will be successful in finding a solution to this problem and that my life will go forth without debilitating headaches and all the other uncomfortable limits that have been imposed on me. I know, too, that my life in health will look a lot different as well, as I am dedicated to helping others with this ailment and I will be grateful for every day I spend outside of my four walls.

I wish health and hope to everyone dealing with a CSF leak!

You can visit Ingrid's blog at: somethingwonderfulweb.wordpress.com



Every month we update our gallery with the latest pictures of leakers and their supporters flying the flag for CSF leaks. If you've got a photo of you or your loved ones sporting a t-shirt, or slurping coffee out of one of our mugs, feel free to send it into us for the next edition of *Leaker Life*: newsletter@csfleak.info



Fancy a CSF Leak Association hoodie, t-shirt or mug? Head over to our online shop: www.csfleak.info/shop

NEWS



Latest news from the Board of Trustees

Our new membership secretary

We are very pleased to announce that Sarah Mead, one of our existing trustees, has taken on the vital role of Membership Secretary.

Sarah has put in a mountain of work to get our membership process ready for opening the organisation up to membership, and she will be our key contact for membership issues going forward.

If you have any queries about membership, please contact Sarah at: membership@csfleak.info

Medical advisory board

As mentioned in the *Message from the Membership Secretary*, we are currently laying down the foundation work for our medical advisory board (MAB). This includes the drafting of *terms of reference* to define its role and responsibilities, and how it will function and operate.

We are also in early discussions with a number of top UK doctors to identify potential members for the MAB. This promises to be a major and exciting project for 2017, and a milestone for CSF leaks in the UK.

More news to follow, so stay tuned to our [website](#) and [social media pages](#), and watch this space!



Valerie McCluskie

On Sunday 25th September 2016, Valerie took part in the River Ness 10km run in order to raise money and awareness for the CSF Leak Association. Here she gives us an insight into the event, her training regime, and the challenge of fundraising!

Thank you for fundraising for the CSF Leak Association Valerie! What made you choose the Association as your charity to fundraise for?

I have known David and Cerian for a number of years and have seen this condition in action, the impact it has had. I wanted to do something concrete to help.

Tell us about the event you took part in... Why did you choose the River Ness 10km?

I ran the River Ness 10km race as part of the Inverness Festival of Running in September '16. I had run this before back in 2009, and knew the course, I also wanted to challenge the older me against the younger me!

How did you train for it?

I'm lucky enough to have a lovely dog, Daisy, to walk and run with and I started out on shorter runs about 2 months before the race to see how we would both get on. I actually entered the race when I was on a 'high' from a super run one day and wanted to challenge myself!

I was pleasantly surprised to find myself enjoying it almost from the first, and my dog Daisy does too!

We increased our mileage gradually so I was comfortable running about 5 miles. Then I also joined a local Facebook running group for women only and found an experienced running 'buddy' who helped me with companionship on runs and some good advice about pace etc.

What was the course like?

It's a lovely open course, starting in a residential area, before descending a little through 2 - 3 miles of woodland on a single track road, and then a long straight into Inverness, finishing in a party atmosphere with goodies like bananas and

popcorn!

Were there any highlights during the race or whilst training?

I have been exceptionally lucky this year with the weather, mostly I've been able to run in the dry and in the sun, and I've seen some fantastic views crossing fields near to where I live on the Black Isle. The autumn colours this year are also breath-taking! Another highlight was beating my 'old record' on the run of 1 hour and 1 minute to finish in 58m 58secs.



What about any low points - how did you get through them?

Not low-points as such, I think I have just been enjoying running too much for that! However I have suffered from muscle-strain particularly in one hamstring, which has meant quite a lot of discomfort and painful sports massages.

How did you fundraise?

I set up a fundraising page with BT MyDonate and then asked virtually everyone I know to sponsor me!

The page is still open until the end of the year, if anyone would like to add a little more to the total: mydonate.bt.com/fundraisers/valeriemccluskie1

Do you have any tips for future fundraisers?

I think probably to think about it well in advance (unlike me who left it to the last minute) - be prepared to be quite forthright in asking for sponsorship - they can only say no (preferably Yes!). Also a few people approached me and emailed me asking about CSF Leaks, so I had to make sure I knew what I was talking about.

Thank you again Valerie, and a huge congratulations to you on beating your PB! Valerie's page is open until the end of the year so there is still plenty of time to donate.



Raise awareness globally

If you're active on social media, why not check out our [Twitter feed](#) and [Facebook page](#)? We publish regular updates, news, articles and announcements about CSF Leaks and related conditions. If you wish to post your own content on social media about CSF leaks, why not use the following **#hashtags** in order to maximise exposure and secure awareness across the globe?



#CSFleak #SpinalCSFleak #headache #IntracranialHypotension #LeakerLife



Visit to the University Hospital in Freiburg, Germany to see Prof. H. Urbach

Sarah Mead talks about her experience of travelling to Germany for treatment in 2015.

Professor Horst Urbach is the Director of Neuroradiology at the University Hospital in Freiburg (Breisacher Straße 64, 79106 Freiburg, Germany). This is the largest university hospital in Germany. Although German is the native language, Professor Urbach speaks fluent English, as do the other doctors and most of the senior nurses at the hospital. The front desk and ward administrative staff only communicate in German but the secretaries in neuroradiology can speak perfect English. (See Direktion in www.uniklinik-freiburg.de/neuroradiologie/team.html). They are used to dealing with foreign

patients.

Prof. Urbach has authored a number of academic papers on diagnostic and therapeutic approaches to intracranial hypotension, including one published in the August 2014 edition of *Der Nervenarzt* ('The Neurologist'). This is where I came across his name on an internet search.



My aim was to find an experienced radiologist who could offer intrathecal gadolinium-enhanced myelography and/or digital subtraction myelography in an attempt to locate my CSF leak. These procedures are currently not licensed in the UK. I wrote to Prof. Urbach directly at horst.urbach@uniklinikfreiburg.de and he replied (in English) with the suggestion that I undergo a three day investigation study under his supervision at the University Hospital in Freiburg. He also asked for my NHS case notes, which I emailed to him.

I made a private appointment through Prof. Urbach's personal assistant, Iris López (iris.lopez@uniklinikfreiburg.de +49 761 270 51810). Iris can also speak English and is very efficient. There is an international patients department (ims.uniklinikfreiburg.de) but I organised everything directly with Iris and the Neurology Department secretary, Petra Lappenbusch (petra.lappenbusch@uniklinikfreiburg.de +49 761 270 53070). A GP referral letter was not required although I told my GP that I was planning to be treated by Prof. Urbach.

I had to make an advance payment of EUR 5614.29 to pay for Prof. Urbach's time, use of the imaging equipment and three nights in hospital. This was Petra's estimate of the total cost. She sent me a letter (in German) with the breakdown of costs and bank account details for payment. Any difference in the actual cost would either be invoiced or credited following my treatment.

I booked flights for my husband and me to EuroAirport Basel Mulhouse Freiburg. I also pre-arranged a taxi to collect us from the airport by sending an email (in German, using Google Translate) to dispo@taxifreiburg.de (www.taxifreiburg.de/leistungen/leistungen_neu.php). The fixed one-way fare is EUR 104.00 and you have to phone them to make an advance payment using your credit card. There is a shuttle bus from the airport to Freiburg but, because of my chronic headache, I preferred to pay a bit more for a taxi to keep the journey time as short as possible. To meet the taxi driver, you have to take the 'France/Germany' exit after baggage reclaim, not the 'Switzerland' exit. The drive to the hospital from the airport is only 45 minutes.

My husband had reserved a room at Hotel Stadt Freiburg which is a functional but very pleasant hotel, just ten minutes walk from the hospital's 'Neurozentrum' where Prof. Urbach is based. I stayed in the hotel with my husband for the first night. The front desk and restaurant staff all speak English. Our room 712 was on the top floor (excluding the suites) and overlooking the front garden. The back rooms overlook a multistorey car park.



HOSPITAL DAY ONE

In the morning, I checked in at the registration desk (Anmeldung) in the Neurozentrum. (My understanding is that the hospital has since opened an international patients checkin desk in another part of the hospital, quite some way from the Neurozentrum). I was required to show my passport and give my home address in England. I was given a medical services agreement form (Wahlleistungsvereinbarung, with English translation) to sign, which gave me the details of my contract with the hospital for their treatment and care.

I was given a wristband to wear, which had my personal information written on it.

My husband was given a family certificate (Angehörigenbescheinigung) that entitled him to a discounted rate at Hotel Stadt Freiburg. The special rate for a double room for one night was EUR 118.00 (2-person occupation) or EUR 86.00 (single occupation). This is a standing arrangement between the hospital and the hotel.

I was then taken to one of the hospital wards ('Station Hoffman' on the 3rd floor) where I was placed in a two-bed room. (A small number of one-bed rooms are available if you prefer not to share. The room has wifi. The food is pretty grim, much worse than NHS.)

Almost immediately, I was transferred in a wheelchair to Professor Urbach's office on the ground floor. He was a gently-spoken, patient man who asked me about my medical history, the reason for my ventricular shunt, and my current symptoms. He then went into some detail about his proposed investigation.

He extremely knowledgeable about CSF leaks, both in terms of detection and treatment. I asked if he was intending to do a digital subtraction myelogram (DSM) with general anaesthetic, but he reported that in his opinion the resulting pictures were not as clear as the pictures produced by a fast CT scan (as performed by Dr. Linda Leithe-Gray in the USA). Therefore, if a diagnostic myelogram did not show a leak, he would then perform a fast CT scan with intrathecal gadolinium enhancement.

Prof. Urbach's plan was to start with a full spine and brain MRI scan (no contrast dye) to see if any CSF leaks could be detected. That was to follow our meeting. He said that day 2 would involve a diagnostic myelogram with iodine contrast, using a tilt table to disperse the dye. Depending on the outcome of this test, day 3 would most likely be a second myelogram with targeted

blood/fibrin patching of the leak sites. He said that blind blood patching was too speculative because there was little evidence that the blood flowed consistently to the leak site.

Prof. Urbach said that any meningeal diverticulae could be a possible location of CSF leaks but that many patients have such cysts with no leak symptoms. His main concern was whether the leak site would be dorsal/posterior or ventricle/anterior (i.e. on the back-facing side of the dura or the side facing into the body). It is much harder to treat leaks on the side of the dura facing into the body. He gave a couple of case history examples (patient from Canada, patient from Italy).

There was no need for me to stay in hospital as an inpatient on day one but I would be required to spend the following two nights on the ward. And if a blood patch was performed, I would spend 24 hours lying flat in hospital and then a further three days resting at the hotel before flying home.

I was taken for an x-ray to check the calibration of my Miethke proGAV shunt. One of Prof. Urbach's assistants (Karim Eid) then explained (in perfect English) the procedure for an MRI; a standard safety talk similar to the information provided prior to an MRI in the UK. The vibration of the scanner was quite intense, as was the heat from the scanning mechanism on my back.

Following the MRI, another doctor (Dr. Christopher Beck) then described the procedures that I would undergo on day two. This was a detailed discussion, and unlike my experience in the UK. I was also shown the room where the myelograms would take place.

Finally, I was taken back to the Hoffman ward, by a lovely English-speaking secretary (Oberarztsekretariat) called Mara Güntert (mara.guentert@uniklinik-freiburg.de) who explained to the ward staff that I needed bloods to be taken. I waited about 10 minutes and then they were taken by an English-speaking phlebotomist. This was to check for thyroid hormone levels and haemophilia. Abnormal samples would increase the risk of adverse reactions to the myelogram.

I was then free to go back to the hotel to stay with my husband for the night. It wasn't necessary to stay on the ward.

HOSPITAL DAY TWO

I reported back to the ward at 7:45am and by 8:30 I was being wheeled in my bed to the myelography room.

Dr. Urbach himself performed the myelography, which took about 40 minutes. He was assisted by a team of four doctors. He used a contrast mix of 0.5ml gadolinium with 15ml iodine. This was injected, slowly and under xray guidance, intrathecally in my lower lumbar region. The table was tilted and I felt an explosive pain when the contrast ran into my head. The staff were very sympathetic and gave me some time to settle. They had their backs to me and were continuously monitoring the xray images to check that the contrast had spread along the length of my spine.

After this I was wheeled down to the CT scanner where images of the dural sac and meningeal space were made. This took about 5-10 minutes.

After this, I was wheeled away for an MRI scan. (Note that the gadolinium and not the iodine would show up on the MRI images.) The MRI was long, about 1 hour and 40 minutes.

Prof. Urbach came to visit me after the scan. He said that there was no evidence of any leaks on any of the images. He observed that I had many (>15) meningeal diverticulae (MD) which were small but he could not see any leaking at the MD locations. There may still be a possibility of tiny leaks at the sites of the MD that were too small to be seen on the images. He noted that the dural sac was belling at its base, probably because of the tissue elasticity due to my Ehlers-Danlos Syndrome (EDS) Type 3.

We agreed that he would carry out a blood patch tomorrow to target the MD. I mentioned the technique used by Dr. Gray-Leithe which involved guided patches at each of the MD locations. Prof. Urbach had done this in the past did not think that there was much evidence that this technique would be more successful in my case.

I was taken back to the ward where I was later visited by the head of neurology, Professor Sebastian Rauer, accompanied by Dr Cornelia Fischer. They were very nice but Prof Rauer explained that the lack of evidence of leaking from my diagnostic images meant treating me with a blood patch was speculative. Dr. Fischer told me that my blood tests yesterday revealed that I had an underactive thyroid (like Mum).

HOSPITAL DAY THREE

I discussed with Prof. Urbach the alternative of a single blood patch at the L1 level with contrast material (his preferred method) or guided blood patches at the location of each meningeal diverticulae (MD) (my suggestion). In the end, I opted for his method.

The procedure was performed in the CT tomography room around 9:30am. Prof. Urbach injected some contrast material into my dura and monitored its dispersal, which was aided by tilting the table.

The purpose of this was to check that the blood travelled to the site of the cysts. Inserting the line into my back was very painful in the insertion area, in my stomach and down my legs.

Before Prof. Urbach arrived, my right hand was cleaned and gowned, a cannula was inserted and the assistant doctor drew off four large vials of blood (about 40ml). Prof. Urbach injected this gradually and alternately with contrast dye (iodine again) all the time monitoring the CT images to check that the blood had flowed up the spinal canal.

Once Prof. Urbach was satisfied that he had injected as much blood as was possible (when I could bear the pain no longer) he removed the epidural needle and I was taken for a 5 minute CT scan.

After the CT scan, I was asked to lie flat and still for one hour. The whole procedure took about an hour. Prof Urbach said that diamox could be prescribed if I had a high pressure rebound headache. I was then wheeled back to the ward. The nurse on the ward gave me an injection of MSI (liquid

oxycodone) in my stomach to reduce the pain in my back and legs.

I was visited again by Prof Rauer and Dr Fischer. They said that they had just had a meeting with Prof Urbach and reviewed the images. Since yesterday's scans showed no evidence of leaking, it was difficult to predict if the blood patches would work. Prof Rauer said that the CSF pressure that they measured (15) was normal.

I agreed that Dr Fischer would write her report in German.

Dr Fischer asked if I had tried theophiline. No, but I had had a caffeine infusion. I had been informed that theophiline took 6 months before it had any effect. At the time it was thought that a caffeine infusion would be faster (although it was ineffective in my case).

NB. In the UK you are normally asked to put on a hospital gown, compression stockings and paper knickers before being taken down to theatre for treatment. Here, I was wheeled down wearing whatever I had on at the time (1st day my dress and 2nd day my pyjamas).

When I arrived in theatre I was asked to remove my clothes, leaving on my own knickers, and put on the gown in front of everyone who happened to be there, male & female. I didn't care by this point, but if you would be uncomfortable in this situation do make sure you ask to change in private!

It was also interesting to see that, although all the staff wear white jackets (sleeves rolled down which you wouldn't find in the UK), underneath they tend to wear very casual clothes t-shirts and jeans, some torn, some not!



HOSPITAL DAY FOUR

Treatment had finished so I left hospital mid-morning to return to the hotel with my husband. Prof Urbach agreed to see me at 9am on day seven (Monday) before my flight back home. The discharge procedure was quite informal I just

informed the ward staff that Prof Urbach had said I could leave and they said goodbye to me.

Prof. Urbach told my husband that, according to my images, the blood patch had not reached the very top levels of the spine. (It would have done, had I been able to bear the pain.) However, he said that the volume inside the dura would be decreased by the scarring catalysed by the blood patch. He thought that this might give me some relief.

I spent the rest of the day in the hotel room catching up on sleep. My back was extremely sore.

DAY FIVE

Lying down most of the day although I did make it down to breakfast.

The nature of the headache pain has changed. It is now slightly worse when I lie down. Possibly a high pressure headache following the blood patching? The dominant pain though is in my back.

Slept OK. Husband went sightseeing in Freiburg.

DAY SIX

Another day of rest in the hotel room.

Some nausea but otherwise same as yesterday. Headache is 3/10 on the pain spectrum when I'm sitting up. I have halved my dose of morphine to 5ml.

The pain in my head is less when I stand. It gets worse when I lie down. This is the reverse of my normal symptoms.

DAY SEVEN

Met Prof. Urbach in his office at 9.00am. I informed him that my headache had diminished. Headache is 3/10.

He was pleased to hear that the blood patch has had a positive effect. I explained that my head was worse lying down now. He agreed that it was a high pressure reaction. He suggested that I should wait three months, see how it goes and then repeat the blood patch, if necessary. He advised against taking diamox because it would cloud analysis of my recovery.

Prof. Urbach said that the scan images showed that my blood patch travelled halfway up my thoracic spine (about T6). I had about 20 meningeal diverticulae (MD).

He was against injecting targeted blood patches at every MD location. He said that he preferred his method of patching the epidural space and controlling the flow of blood up the spine. He argued that this method would ensure that the branches between the thecal sac and MDs would also be sealed.

He also said that he only used fibrin for localised patching as it does not flow. He would inject fibrin only if he could positively identify a leak site. Each injection costs 500 EUR so it was not a treatment to apply speculatively.

I asked Prof. Urbach if I could recommend him to my fellow patients. He said yes but cautioned that it is an imprecise science.

My husband has suggested that I keep a lid on my optimism. However, the immediate signs are encouraging.

I was given a CD-ROM of all my scans.


Back to the hotel to check-out and fly home.


Final note: I started taking Diamox at the rate of one quarter of a 250mg tablet 4 x daily on Thursday 1st October. It has made an incredible difference. I can now be upright for as long as I'm not tired. I was still taking all my painkillers after the trip, but the difference was that they now totally controlled the pain. I remained on them for another few weeks before coming off them slowly; Prof Urbach warned me to take it slowly so that my body had time to compensate for the sudden HP, as we know that my rate of CSF production was much higher than normal - probably as a result of my body trying to heal itself or compensate.

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