



Message from the Editor

Hello, <<First Name>>.

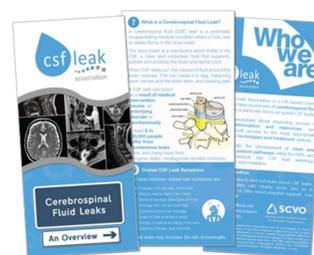
Welcome to the fourth edition of Leaker Life. Since our last edition, many exciting developments have been taking place for the association.

The first quarter of 2017 saw the very first Spinal CSF Leak Awareness Week, held between 26 Feb and 4th March. The event was spearheaded by the Spinal CSF Leak Foundation, but received tremendous global support and appealed to those with an interest in CSF Leaks from near and far.

Among the events held were three live online Q&A sessions, featuring top experts in the world of CSF Leaks: Dr Wouter Schievink, Dr Peter Kranz and Dr Ian Carroll. During these sessions a great deal of fascinating discussion took place. In this newsletter we summarise the key points covered.

In order to mark the first Leak Week, two fundraising events also took place here in the UK and we share the successes of the events and the experiences of the fundraisers.

January saw the grand opening of membership to



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](#)

the association. We have had an impressive number of applicants during these initial months and hope that this will continue to grow from strength to strength. Thank you if you have already joined, and if you haven't yet, but are interested please do have a look at the benefits membership offers at www.csfleak.info/membership

Plans are already well and truly underway for our first AGM, news of which can be found in the newsletter, along with information on becoming a trustee for those of our members who may be interested in joining us on the board.

We do hope you find the newsletter informative and interesting. As ever, we are always grateful to receive feedback about the newsletter and welcome suggestions for future articles. Please do get in contact to share your thoughts and please keep sharing your photos. We love receiving them! In the meantime, once again thank you for your ongoing support.

Polly Walker
Trustee & Editor



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

[Find out more](#)



The end of February saw the launch of the first ever 'Leak Week', a week dedicated to raising awareness of spinal cerebrospinal fluid leaks, running from 26th Feb to 4th March.

Initiated by the US Spinal CSF Leak Foundation, the campaign was dedicated to spreading the word about what a CSF Leak is, and to clearly highlight the associated

symptoms in order to aid diagnosis. As we all know:

Diagnosis >> Treatment >> Better Outcomes.

To coincide with Leak Week, we launched our very own infographic which can be downloaded at www.csfleak.info/uprightheadache and printed out on A4.

Upright headache? Think CSF leak.

1. Headache and head pain
• Often experienced at the front or back of the head, although can vary a great deal in severity and characteristics
• It is often worse when sitting or standing, but may become less positional over time.

2. Head pressure and sensations
• Pressure feeling within the skull
• 'Pulling' sensation from the head to neck.
• Facial numbness, jaw pain and toothache
• 'Crawling' or dripping liquid sensations around top of head.

3. Neck and back pain
• Neck pain, aches and stiffness
• Interscapular pain (stiffness between shoulder blades)
• Generalised back pain (occasionally at nerve roots)
• Rarely, localised pain at the site of the CSF leak.

4. Spinal and cranial fluid leak
• Rarely, large pseudomeningocele may be visible under the skin, however majority of spinal leaks cannot be seen externally
• Cranial leaks may present as fluid leaking from nose, ears and drainage to throat.

5. Eye pain and photophobia
• Pain behind eyes
• Pain when moving eyes
• Sensitivity to bright light (photophobia)
• Visual field changes.

6. Tinnitus and hearing changes
• Tinnitus – high pitched, buzzing and pulsatile
• Ear pressure, popping or feeling of liquid in ears
• Hearing loss and dulled hearing
• Sensitivity to sound (phonophobia).

7. Brain fog and fatigue
• Cognitive impairment (including memory loss, loss of concentration or inability to maintain train of thought)
• Chronic fatigue, lack of stamina and exhaustion.

8. Nausea and taste
• Nausea and vomiting (often worse when sitting or standing)
• Changes in taste (sometimes metallic or salty)
• Cranial leaks may result in fluid discharge in throat.

9. Dizziness and imbalance
• Dizziness (particularly when upright or changing position)
• Sense of imbalance and ataxia (unsteady gait)
• Occasionally, quadriplegia, parkinsonism or other movement disorders.

10. Double and blurred vision
• Vision can become blurred or double vision may be experienced, often worsening after a period sitting or standing
• For glasses users, prescription changes may occur.

11. Vertical position
Intracranial hypotension, is responsible for many CSF leak symptoms. It normally has a prominent postural element; pain to worsen when upright. Sometimes onset may occur immediately, but symptoms can build slowly to become a 'second half of day headache'.

Horizontal position
Symptoms may be entirely relieved or significantly reduced by lying down (often with head lower than feet). The postural element may, however, reduce over time, and lying down may then provide less relief.

Find out more about cerebrospinal fluid leaks
www.csfleak.info/findoutmore
The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC0490318)

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During Leak Week, much coverage was given to the painful and debilitating positional headache that tends to accompany CSF Leaks, which is now also considered an important and under diagnosed cause of new daily persistent headache. It is both treatable and curable, along with the many other neurological symptoms and complications that can be entirely debilitating due to the patient's limited ability to be functional whilst upright. Click [here](#) to view the Spinal CSF Leak Foundation's fantastic new video animation that was launched and shared over and over again on social media, featuring Anna, a 'leaker' who explains clearly what a CSF Leak is.



Three live expert Q and A sessions also took place, as well as sponsored events, and a number of prominent landmarks shone purple across north America. In addition, the Spinal CSF Leak Foundation and the CSF Association joined forces across the globe in a colourful social media campaign, asking supporters to draw or paint blue (representing the CSF Association) and purple droplets (representing the Spinal CSF Leak Foundation) on their hands, arms or face, to photograph it and share on social media using the hashtag **#LeakWeek** to spread the message. Other hashtags regularly highlighted the cause too **#CSFleak** **#cerebrospinalfluidleak** **#uprightheadache**



If you missed the 2017 Leak Week, don't worry! There are still plenty of ways that you can spread the word and support the work we do:

- 💧 Help to raise awareness – tell people about CSF Leaks, hand out leaflets, display your window sticker, wear your wristband, share your story, share our story, use social media, write a blog.
 - 💧 Become a member
 - 💧 Make a [donation](#) to support our work
 - 💧 Share our link
 - 💧 Share the [video animation](#)
 - 💧 Organise a [fundraising event](#) - we can help you with ideas!
 - 💧 Support us when you [shop](#) online
 - 💧 Shop for CSF Leak Association merchandise [here](#) and proudly show it off!
 - 💧 If you're interested in [working with us](#) we'd love to hear from you!
-

Join us for 3 LIVE Expert Q&A Sessions

March 1 to 3 at
11 am PST / 2 pm EST

#leakweek

@Spinal.CSf.Leak.Foundation



Peter G. Kranz, MD
Radiology / Spine Intervention
Duke University
March 1



Ian Carroll MD, MS
Anesthesiology / Pain Medicine
Stanford University
March 2



Wouter I. Schievink, MD
Neurosurgery
Cedars-Sinai
March 3

This is part 1 in a 3 part series summarising the three live Q & A sessions which took place during Leak Week, involving three of the worlds leading specialists in CSF Leaks.

We wish to express our sincere gratitude to [The Spinal CSF Leak Foundation](#) for organising these sessions, and for also allowing us to feature this summary in our newsletter. In addition, we wish to express our thanks to Becky Hill for the time and hard work she has given in transcribing the sessions.



DR KRANZ - INTERVENTIONAL NEURO-RADIOLOGIST
Duke University Hospital, North Carolina, USA.



Dr Kranz works closely alongside Dr Gray-Leithe, who is renowned for her extensive work within the field of CSF Leaks.

10 years ago the team at Duke University Hospital began to notice an increase in the number of CSF Leak cases – they now receive a lot more referrals and have learnt much over the years.

1. HOW LONG AFTER AN EPIDURAL BLOOD PATCH SHOULD ONE EXPECT THE HEADACHE TO GO?

- Leaks caused by needle holes usually respond very quickly to blood patches and response is that often headaches go almost instantly at patching.
- Those with spontaneous leaks normally take longer and patients can experience RHP (Rebound High Pressure). Headache reduction can take hours to days to be apparent but the team normally assesses after 1 week as to whether the patch has been successful. (The patient may also still have RHP of course).

2. TESTING AVAILABLE AT DUKE?

- MRI - 75% show brain evidence of leak.
- They then use CT myelogram - 50% of spinal leaks will show on myelogram.
- CSF pressure is also measured when a myelogram is carried out and 30% with leaks will show below 6 on pressure test.
- Assessment / diagnosis is also made based on history and symptoms.

3. CHRONIC HEADACHES FOLLOWING TREATMENT?

- First thing to rule out is Rebound High Pressure. This often presents in a different position to low-pressure headaches - around the eyes/ forehead etc. It can be managed using Diamox.
- However an on going leak would also be considered.

4. IF SOMEONE IS NOT ACTUALLY LEAKING BUT WAS PATCHED WOULD THEY EXPERIENCE GREATER REBOUND PRESSURE?

- People might have some pressure fluctuation if they were not actually leaking but have an Epidural Blood Patch.
- A patient who does have a leak may experience Rebound High Pressure because over time the body goes under physiological changes to compensate i.e. not sure

exactly why - but veins around spine might dilate, you start producing more spinal fluid and when leak gets shut off from patch the body might take a while to reduce the ways in which it has compensated.

5. HOW ARE DUKE UNIQUE IN THEIR TREATING OF LEAKS?

- They have developed certain techniques, for example, in helping to capture some faster leaks. They scan within a 1-2 mins of putting contrast in which helps capture fast/ transient leaks.
- Duke also carries out a procedure to detect fast leaks or venous fistula leaks. These types of leaks have only been discovered in the past couple of years and involve the CSF escaping into a vein around the spine.
- Patching is targeted using either blood or fibrin glue.
- Other places have different techniques but the important thing is that the patient needs an experienced physician.

6. HOW COMMON IS IT TO EXPERIENCE REBOUND HIGH PRESSURE AFTER A PATCH? CAN IT CAUSE TARLOV CYSTS OR SPRING A NEW LEAK?

- This is currently an area of active research.
- At Duke, the team sees Rebound High Pressure in some form in about 50% of those getting patched but more severe cases in about 10% - 20% of those getting patched.
- After surgery it's a little less common.
- Those with newly recognised venous fistula tend to get really bad High Pressure afterwards. So with that group of patients the team will try and treat PRE-surgery for RHP to prepare the body.
- So it all varies a lot. It's an area of interest - in how to prevent it, what happens to the body and what sorts of things predispose you to it. This is currently being researched.

7. WOULD MULTIPLE PATCHES LEAD TO MORE HIGH PRESSURE?

- With any patch you are at risk. If you have already had a patch and then have another while in RHP it may well push your pressure up higher. It's very important before you get another patch to work out if a patient has persistent lower pressure headaches or higher pressure headaches. They will often check pressure readings again to establish that.
- But you are unlikely to have a higher chance of RHP with the 3rd patch compared to the 1st patch if starting from the same low-pressure state. But if pressure rises in between patches it would put you at higher risk.

8. WHAT IS THE PROCEDURE AT DUKE FOR PEOPLE WUTH UNSUCCESSFUL PATCHING PARTICULARLY THOSE WITH CYSTS?

- Everyone is different and I would hesitate to put protocol on it.
- CYSTS: along nerve roots exiting the spine there are frequently small diverticulum / out pouches / cysts. People without leaks often have those cysts too. Just because you have cysts doesn't mean you have a leak. But those cysts can be predisposed to leaking.
- There are certain configurations of cysts and types of cysts that are more suspicious than others.
- There was a time when every cyst would be patched that could be found. However lessons have been learned and how and when patching takes place is a little more selective now.

- Everyone is different and would be assessed in imaging.

9. TYPES OF PATCHES CARRIED OUT AT DUKE -

- FIBRIN GLUE: This is a biological product; it is not necessarily better than blood, but it is different. It gets sticky faster and spreads less than blood and there are times when the location of a leak is known and so glue is better for targeted patches. Glue is always used WITH blood.
- BLOOD - better when needed to spread i.e. for Blind Epidural Blood Patching or when the needle can't be placed close to the leak site.

BLIND PATCHING

- You don't need to find a leak to diagnose the condition. Some people they will have no evidence apart from symptoms.
- Depending on complexity of leak etc. On average I estimate it will take 2-3 patches to get it sealed. Some people are lucky and 1 patch does it. Others patched multiple times and they have a hard time sealing the leak. Some require surgery.
- The outcomes of patients being treated with an Epidural Blood Patch are being tracked now. Will have data out on that in next 6 months to a year. So better info then.

10. WHAT IMAGING SHOULD A PROSPECTIVE PATIENT HAVE? SHOULD THEY SEE A NEUROLOGIST FIRST OR RADIOLOGIST?

- There are multiple people who can take care of leaks. Neurologist, Neuroradiologist, Neurosurgeon and Anaesthetist.
- The important thing is seeing someone with experience in the condition. Often people see a neurologist first. One of pioneers is Neuro Dr Mokri at Mayo Clinic.
- Duke will ask for a brain MRI with contrast before seeing a patient for spinal imaging.

11. SKULL BASE LEAKS – DO THEY CAUSE INTRACRANIAL HYPOTENSION?

- Generally not. They present with different symptoms from spinal leaks. If you can picture CSF as a water tower. The pressure is greatest at the base of spine. So people with leaks lower in spine get positional headaches because that's where the pressure is greatest. But with skull base the skull is often in negative pressure upright anyway so if leak is there, headaches are usually not positional. Patients complain mostly of fluid coming out of their nose or ears or they catch meningitis. Sometimes headaches are present but they are not positional. The patients often leak more when the head is down between their knees and they experience a gush of fluid.

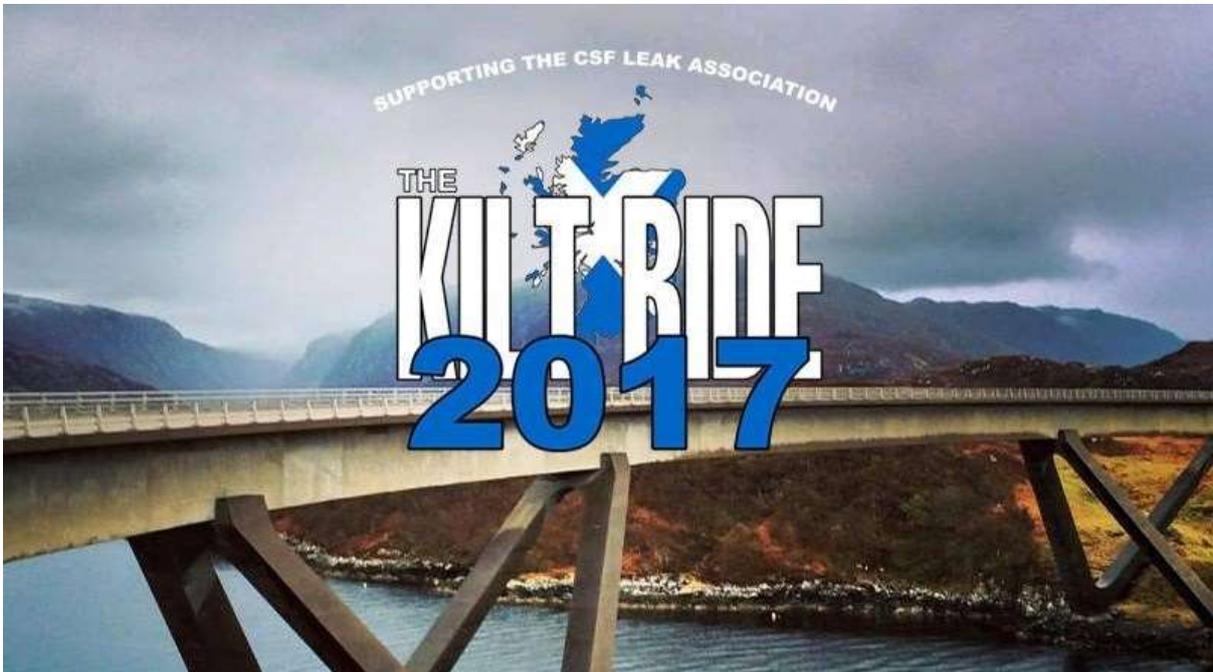
12. IS IT STANDARD PROCEDURE TO TEST OPENING PRESSURE FROM A MYELOGRAM?

- It can help establish baseline to access later.
- For instance a patient may be leaking but have pressure in the normal or even high range. Knowing that base pressure can help in the future if they are concerned about RHP etc. They can compare pre treatment and post treatment pressures.
- When talking about 'normal values' for CSF leaks or high pressure old diagnostic criteria can be very unreliable. New research and the experience of the team at Duke shows many people who didn't fall into diagnostic criteria for leaks or high pressure do actually do have a leak/ RHP.
- They are on the threshold of being able to recognise new opening pressure criteria but more research needs to be prioritised on this to help headache care in general.

You can view this Q and A session via the link below:



We wish to offer our thanks to Dr Kranz for taking part in this informative and fascinating Q and A session. We hope the future may bring more opportunities for further interactive sessions.



The Kilt Ride returns for 2017!

Following the success of the inaugural Kilt Ride in 2016, this year's event, organised by Ray Michael (aka 'The Scotorian Biker'), promises to be bigger and better this year!

As many of you may recall, on 28th May 2016, some 100 tartan-clad bikers arrived

on the banks of Loch Ness as part of a two-day 500-mile ride in support of the CSF Leak Association. Called 'The Kilt Ride 2016', the event was the world's first ever large-scale awareness and fundraising event for cerebrospinal fluid (CSF) leaks.

The fantastic two day event, the brainchild of Ray Michael, raised £1458 for the CSF Leak Association and saw a convoy of motorbikes of all shapes and sizes, learners and old hands, rally to the support of leakers across the UK by travelling around the country, from the Scottish Borders to the Highlands, taking in some of Scotland's most iconic sites and scenery.

This year the event will be held on Friday 26th May – Monday 29th taking in the north west coast of Scotland and parts of the fabulous North Coast 500 route.

If you'd like to get involved, or follow the progress of the bikers, check out the website [here](#) or follow the Facebook event page [here](#)

A huge thank you once again to Ray and his team on behalf of the CSF Association!



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www.csfleak.info



Help us fix
cerebrospinal
fluid leaks





The CSF Leak Association is open for membership: come and join us!

We are delighted to announce that the CSF Leak Association opened for membership in January 2017.

As a membership organisation, we rely heavily on the fantastic support and generous encouragement of our supporters in the work that we do. Without this dedicated help, we could not function and would be unable to continue to raise awareness of cerebrospinal fluid leaks and push for positive change.

Whether you're an individual or an organisation, based in the UK or further afield, if you share our [aims and objectives](#) and benefit from the work that we do, why not join us and get involved?

Our aim is to provide support to all sufferers of cerebrospinal fluid (CSF) leaks and, in addition, their family, friends and medical advisers. Whether the leak is caused by injury, accident, a pre-existing medical condition, be it spinal or cranial leak, we will do all we can to supply you with the information you need to know.

If you think you may have a CSF leak but have not yet received a positive diagnosis, we can help you find a consultant in your area that has experience of treating patients with CSF leaks. If you already have a diagnosis, we can help explain all the medical terms and procedures that you may encounter on your way towards treatment and resolution.

We understand that this condition can be debilitating, life-changing and sometimes frightening. We hope that the information contained within our membership resources, publications and on our website will give you will help to take the edge off some of these worries and reassure you that you are not alone.

The CSF Leak Association is run by people who all have personal experience of CSF leaks. Many of our trustees and volunteers have suffered, or are still suffering, with the effects of a leak, while others are partners or family of a 'leaker' (as we like to be known!). We firmly believe that it is vital that those offering support understand completely what you are going through, and we know how important it is to know that support is out there.

Membership Benefits

As a new member of the CSF Leak Association, you will be sent a welcome pack, which includes:

- Welcome letter
- Membership card
- Medical accommodations cards
- Window sticker
- Awareness wrist band
- A copy of our latest factsheet
- Printed copies of our *Cerebrospinal Fluid Leaks: An Overview* leaflet

Membership benefits also include:

- Access to our members' mailing list
- Access to our online membership system
- Access to our members' network directory
- Access to our membership library
- Right to attend and vote at members' meetings

You will also be eligible to receive a full copy of our quarterly e-newsletter, *Leaker Life*, as soon as it is published (in the near future, non-members have access to limited new content and back-issues only).

For more information about membership, the charity, what we do and how we operate, please download a copy of [our guide to CSF Leak Association membership](#).

There are 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 is also available to those under the age of 16 at £5.00 per year. Junior supporters are able to vote or stand for election, but will enjoy all other benefits of membership.



All new members receive a 'Stop the Brain Drain' window sticker, a wristband and a membership card in their pack.



Calling all Android Mobile Phone and Tablet owners!

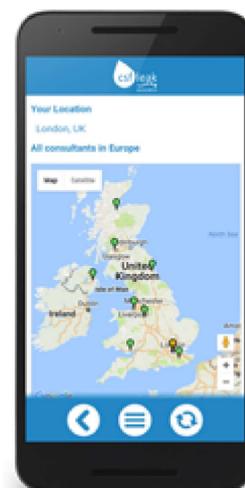
We are delighted to announce the release of our brand new Android app for CSF leakers. It's absolutely free and available to [download from the Google Play store](#).

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.



Name: Chris Plant
Home town: Derby, UK
Type of Leak: Cranial / Traumatic
Current Leak Status: Sealed and Healed!

In this issue, the spotlight is on Chris Plant... Here is the story of Chris' traumatic cranial CSF leak in his own words. Thank you Chris for sharing it with us!

'I was twenty years old and I'd spent the summer in the US competing in Triathlons. This was followed by a couple of weeks in the South of France in the Ardeché Gorge Rock climbing and having a most excellent time, then a week in Chamonix - the centre of world alpinism. Life was good, very good. I had a dream of becoming an International Mountain Guide which would have meant a life of sharing my passion for mountain sports, rock climbing, ice climbing skiing etc etc.

On the last day of the holiday in Chamonix, a friend and I decided to have an easy day on the Glacier des Bossons. It should have been a calm, low key, no stress day. It wasn't. I slipped and banged my head, knocked myself out and ended up 40ft down a crevasse unconscious. The upshot was I had sustained one or two bumps and bruises. I had in actual fact broken my right leg in four places which had to be pinned back together, I had a compressed wedge fracture to vertebrae in my back at level L1 & L2, and I'd broken my nose.

What we didn't know at the time was that I had also fractured my skull. This didn't become apparent until a few months later when the trauma started to subside and Cerebrospinal Fluid (CSF) started dripping out of my nose. I thought I had a cold. A cold it was not. At the time I was having regular orthopaedic checkups. I been told that it was likely I'd be on crutches for at least six months, in the world of Chris that was a challenge and to me, I was going to do without my crutches in three.

I had my regular appointment with the consultant and had shown him that I could walk without the aid of crutches. However I did let him know that I had been having really bad headaches, at which point an urgent X-ray was arranged. The results revealed that I had been taking outside air up into my cranium which had compressed my brain to two thirds the size it should have been.

I was asked to go home, pack a bag, and to get to the Queens Medical Centre for seven pm, that would be great. I was given antibiotics and an 8 hr operation (Anterior Fosa-Craniotomy) followed by a week on the Neurological ward, and thankfully that was enough to seal the hole that was in my head.



Chris following his Anterior Fosa-Craniotomy

That was nearly thirty years ago. People have since called me stubborn; I prefer to see myself as determined and strong-minded. I listened to what people said (my family - I thank you) and made my own mind up. I believed I would get better and I have, and I'm stronger because of what happened to me. It may seem strange but I'm happy it did happen because I can now use my experience to help others. I had to put a few things on hold, but hey that's life! Life is not a rehearsal, so get out be kind to those who need it and enjoy it'.



Chris enjoying life now!



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



CSF Leak Association AGM 2017

The charity's Annual General Meeting (AGM) will take place at our registered office in Strathpeffer at 7pm on 2 May 2017.

All of our members are eligible to attend in person. Members may also join the meeting as a teleconference using Skype (slots permitting). Voting can be carried out in person, via Skype or by proxy.

For our members, more information on the forthcoming AGM, including copies of the agenda and all relevant papers, can be found here (requires login): www.csfleak.info/members/agm

BECOMING A TRUSTEE

Being a charity trustee can be fun, rewarding and enables you to give something back. We've achieved a lot in the last year and look forward to doing much more, but we can only do it with a good team of trustees at the helm.

We recognise that the prospect of being a trustee may seem daunting, however being a trustee with us will allow you to give what you can without any requirement for more. All of our current trustees are either CSF leakers themselves or carers. We know the challenges this involves and therefore volunteering with us fits around that.

We meet through Skype once a month for up to two hours and whilst regular attendance is encouraged, we also recognise that health or other commitments have to come first. Most Trustees put in about 3-4 hours in total per month but this can vary depending on people's needs.

We also like to work to people's strengths so would be keen to hear what makes you tick and what you enjoy doing. Volunteering should be fulfilling, not onerous. If you'd be interested in joining us, feel free to [click here to download the application pack](#) or visit our [members' library](#) for more information on what being a trustee involves.



Medical Advisory Board

Our annual report, which will be presented at the AGM, will outline a lot of the projects that we have been working on during the past year. One notable initiative has been the preparatory work carried out for the establishment of our medical advisory committee (MAC).

We have compiled, with the assistance of both our members and a number of UK specialists, a shortlist of doctors with a view to extending an invitation to them to join our MAC. We have also been working on an operating framework and terms of reference for the committee, and hope to make good progress on its establishment in 2017.



Jenny Pople

I had my first spinal CSF leak in 2012 and a second in 2015. During my first leak I was diagnosed really quickly but not offered any treatment and struggled to find good quality information about the condition, treatment options and availability, and

specialists who could help me manage the symptoms. I'm now passionate that everyone in the UK should be able to access good quality, accurate, information on the condition, get effective diagnostic scans, management from a knowledgeable Clinician and rapid access to effective treatment. The CSF leak association are doing great work towards these goals and I hope the funds I have raised make a positive contribution to this.



I chose to do a 4 mile sponsored walk at a local nature reserve - Stanwick Lakes. I put on quite a bit of weight and lost a lot of fitness during my recent leak so the walk gave me motivation to try and improve these as well as raising money. The reserve is beautiful any time of year and the scenery and wildlife always put a smile on my face. It's usually one of the first places I try and visit after I've been stuck at home leaking and I feel blessed to have such a scenic place so close to where I live.



To prepare, I've gradually built up the distance I can walk over the last 3 or 4 months. I did quite a bit of training during the Christmas holidays when I had some spare time away from work.

I did the walk alone. The lakes are very scenic with lots of wildlife. It is quite exposed but I love feeling the power of the elements. The highlights were all the friendly people who I met and said hello to, and the hot mug of tea with a fantastic view in

the visitor centre at the end. The low point was the drizzle as I drove over there but the rain stayed away. The walk was also a chance to reflect on how far I've come in my recovery.



My tips for fundraising... make it personal and a bit of a challenge for you, it doesn't need to be a marathon! You could be sponsored to read that book you've always meant to or do some creative writing. Consider holding a coffee and cake morning with a few friends at home. I love anything crafty and did some charity sewing when I was stuck at home. Tell all your generous friends and family!

Jenny's fundraising page remains open if you would like to pledge your support -

<https://www.justgiving.com/fundraising/Jennifer-Pople>

Polly Walker

On the evening of Tuesday 28th February, I caught the train into London and made my way to the Southbank where we were meeting for a briefing prior to the big event.



Scott Bell, from UK Fire Walk and world record holder for fire walking, talked us through what to expect and the main dos and don'ts. He was an engaging and interesting speaker and most importantly, was incredibly reassuring about this crazy thing that we were about to embark on!

The main points that were most essential to our safety were to walk briskly without running, no stopping on the coals for photos! Not to turn on the coals and to ensure we wiped our feet thoroughly on the wet grass once exiting the coals. And if we so desired, we could chant 'cool wet grass cool wet grass' or 'damp moss damp moss' as we walked the coals but the mind over matter approach wasn't essential...

We headed outside into a bitterly cold February evening to an area of grass by the river Thames. The air was thick with smoke, the flames roared, the coals were being raked and a good sized crowd had already gathered. As I removed my shoes and socks off and stood nervously in line on the cold grass, I watched on as other fundraisers walked the coals...



Before I knew it, I was at the front of the queue, everyone was cheering and I was

asked to step forward and start my walk... firstly across the wet grass, moving onto the glowing coals. As I stepped across the crunchy coals I braced myself for the pain, one step, two steps, three....six, seven, eight...before I knew it I was exiting the coals and wiping my feet on the cool, muddy grass. I had a few 'hot spots' on my feet which I could only compare to the feeling you might get when walking across really hot sand, but otherwise I was unhurt and feeling quite exhilarated! So much so, that I went on to walk the coals again!



Fire walking was never an activity I would have considered prior to suffering a CSF leak. I have participated in lots of fundraising activities in the past that have always been very physical – long distance walks and runs, abseiling etc. I was mindful that this time 2 years ago, merely getting myself out of the house and to the railway station would have been an impossible feat, let alone travelling into and across London, to sit for the hour long briefing, to stand in line and walk the coals and then make my way home again. Even though my physical activities are restricted by my leak, I am still in an extremely fortunate position to be functional and able to consider participating in an activity such as this in order to fundraise for the association and to raise awareness of CSF Leaks.

My sponsorship page is open for another couple of months and any donation is very gratefully received:

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



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 #uprightheadache



Leaker's A-Z : C through D

Health-related terminology can be confusing at times, particularly to those without a medical background, with limited experience dealing with doctors or hospitals or who are new to a particular condition or illness.

We have prepared an alphabetical list of some of the most commonly used CSF Leak terminology on our

Chiari malformation consists of a downward displacement of the cerebellar tonsils through the foramen magnum (the opening at the base of the skull), sometimes causing non-communicating hydrocephalus as a result of obstruction of cerebrospinal fluid (CSF) outflow.

website. Below is some of the terminology that start with C or D. We will share further terminology in future editions.

Cauda Equina

The cauda equina (Latin for “horse’s tail”) is a bundle of spinal nerves and spinal nerve roots.

Cerebrospinal Fluid / CSF

Cerebrospinal fluid (CSF) is a clear colourless bodily fluid found in the brain and spine. It is produced in the choroid plexus of the brain. It acts as a cushion or buffer for the brain’s cortex, providing a basic mechanical and immunological protection to the brain inside the skull, and it serves a vital function in cerebral auto regulation of cerebral blood flow.

The CSF occupies the subarachnoid space (the space between the arachnoid mater and the pia mater) and the ventricular system around and inside the brain and spinal cord. It constitutes the content of the ventricles, cisterns, and sulci of the brain, as well as the central canal of the spinal cord.

When a hole or tear forms in the dura, CSF leaks out. This is known as a CSF leak and can lead to Intracranial Hypotension. A CSF leak in the head can substantially raise a patient’s susceptibility to meningitis, whereas a spinal leak discharges CSF into the surrounding tissue and a patient’s risk of developing meningitis is no higher than the average person.

Cerebrospinal Fluid / CSF Fistula

A CSF fistula is a term generally interchangeable with ‘CSF leak’.

Cerebrospinal Fluid / CSF Leak

A cerebrospinal fluid leak syndrome (CSF leak) is a medical condition in

Choroid Plexus

The choroid plexus is a plexus in the ventricles of the brain where cerebrospinal fluid (CSF) is produced. The choroid plexus consists of modified ependymal cells. CSF is recycled (flushed) 4 times per day in order to clean out metabolites and toxins. The choroid plexus must produce about 500ml of CSF per day (or 21ml per hour).

Coccyx

The coccyx, commonly referred to as the tailbone, is the final segment of the vertebral column in tailless primates. Comprising three to five separate or fused vertebrae (below the sacrum, it is attached to the sacrum by a fibrocartilaginous joint, the sacrococcygeal symphysis, which permits limited movement between the sacrum and the coccyx.

Computed Tomography / CT

Computed Tomography (CT) is a medical imaging technique that uses computer-processed x-rays (ionising radiation) to produce tomographic images (virtual ‘slices’) of specific areas of the head and spine, allowing doctors to see what is inside it without performing surgery. CT imaging is sometimes used in combination with intrathecal contrast.

Digital Subtraction Myelography / DSM

Digital Subtraction Myelography (DSM) is an imaging technique used to locate CSF leaks. This imaging technique uses intrathecal contrast (contrast added to the cerebrospinal fluid), X-rays and a computer to create detailed images.

DSM is a very high resolution type of imaging that generally focusing on sections of the spine, rather than the whole spine, and is often carried out under general anaesthetic to reduce

which the cerebrospinal fluid (CSF) held in and around a brain and spinal cord leaks out of the surrounding protective sac, the dura. It may occur through trauma, following surgery, due to atypical bone growth and other skeletal anomalies or for no apparent reason.

Cerebellar Tonsils

The cerebellar tonsil is analogous to a rounded lobule on the under surface of each cerebellar hemisphere. It is located close to the Fourth Ventricle, towards the rear and bottom of the brain, where it meets the spinal cord.

Cervical

The cervical section of the spine comprises seven bony vertebrae, typically referred to as C-1 to C-7, with cartilaginous discs between. The neck supports the weight of the head and protects the nerves that carry sensory and motor information from the brain down to the rest of the body.

In addition, the neck is highly flexible and allows the head to turn and flex in all directions. From top to bottom the cervical spine is gently curved in convex-forward fashion. It is the least marked of all the curves of the column. CSF leaks are commonly found at or around the junction of the cervical and thoracic spine.

Chiari Malformation / Arnold–Chiari malformation

Chiari malformation, also known as Arnold–Chiari malformation, is a malformation of the brain.

the potential for movement adversely affecting clarity.

This type of scan is not, as of yet, widely available globally.

Directed Blood Patch

A directed blood patch is a blood patch where fluoroscopy is used to guide the placement of the epidural needle. This ensures that the needle is accurately placed and avoids puncturing the dura or damage to the patient's nerves and spinal cord. A directed patch usually involves the injection of a small amount of autologous blood and is more common for patches in the thoracic and cervical regions of the spine, where incorrect needle placement could have a significant adverse effect.

Dura Mater

Dura mater, or simply the dura, is a thick membrane that is the outermost of the three layers of the meninges that surround the brain and spinal cord. The other two meningeal layers are the pia mater and the arachnoid mater. The dura surrounds the brain and the spinal cord and is responsible for keeping in the cerebrospinal fluid. A hole or tear in the dura allows cerebrospinal fluid to leak out and is known as a CSF leak.

You can view our full our full A to Z of terminology on our website, or download it in PDF format here:

www.csfeak.info/csf-leak-terminology



CSF Leak Association Shop and Merchandise

Did you know that the CSF Leak Association, in partnership with Teemill, has an online shop, where you can buy a range of CSF Leak Association-branded clothing and gifts.

Unlike many similar bespoke online clothing platforms, Teemill is located in the UK; printing is carried out in the UK, and items ship from the UK, all within a matter of days. Teemill also ships internationally at very reasonable rates. The quality of the garments is all very good, and production is ethical, low carbon and organic.

For every item sold, the CSF Leak Association will receive a proportion of the profit to go towards the work that we are doing to support sufferers and progress our aims. As an example, for every t-shirt sold at £19, £4.50 will come to the Association; so you help raise the profile of CSF leaks and help us fundraise at the same time!



To visit our online shop, please click on 'shop' in the main menu on the CSF Leak Association website, or visit: www.csfleak.info/shop

PS. Be sure to post a selfie online when you receive your lovely new things, with a brief explanation of what a CSF Leak is and the hashtags **#CSFleak** and **#UprightHeadache** to spread the word even further.

Thank you and happy shopping!



If you would like to network with other CSF leak sufferers or their supporters, to share your experiences of the condition, diagnostic techniques and treatment options, why not head over to the Spinal CSF Leak Inspire community?

The Inspire Community is a safe, moderated forum co-managed by ourselves and our friends at Inspire and the Spinal CSF Leak Foundation. You can choose to remain anonymous if you would like and have control over what information you divulge and how it is used.

You can access the community here: www.spinalcsfleak.inspire.com

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