



## Message from the Trustees

Hello, <<First Name>>.

Welcome to the Winter edition of Leaker Life.

Once again it has been a busy time for the CSF Leak Association, and you will see from our Business Plan that we intend to continue forging ahead in 2019.

We introduce Pete Marnick, one of our hardworking and dedicated Trustees, and hear how he became a 'Leaker'. We have attended both the Headache Academy and RAREfest, and were delighted to raise awareness of CSF leaks via our hugely popular animation. THANK YOU for voting for our animation to be shown - it really was a hair raising few days as we watched the vote count creep higher and higher!

As always, please do get in touch if you have a suggestion for a newsletter feature, if you have a story, a photograph or a talent to share.

Once again, thank you for your tireless support over this year. Happy Christmas!



The countdown is on to  
Christmas!  
Read on to find out how  
you can help the  
Association as you plan  
your festive period...



Thank you for voting!



This edition, sees our Trustee Pete Marnick share his leaker story. Thank you Pete!

**Name: Pete Marnick**

**Age:51**

**Leak location: Lumber Spine at L4-L5**

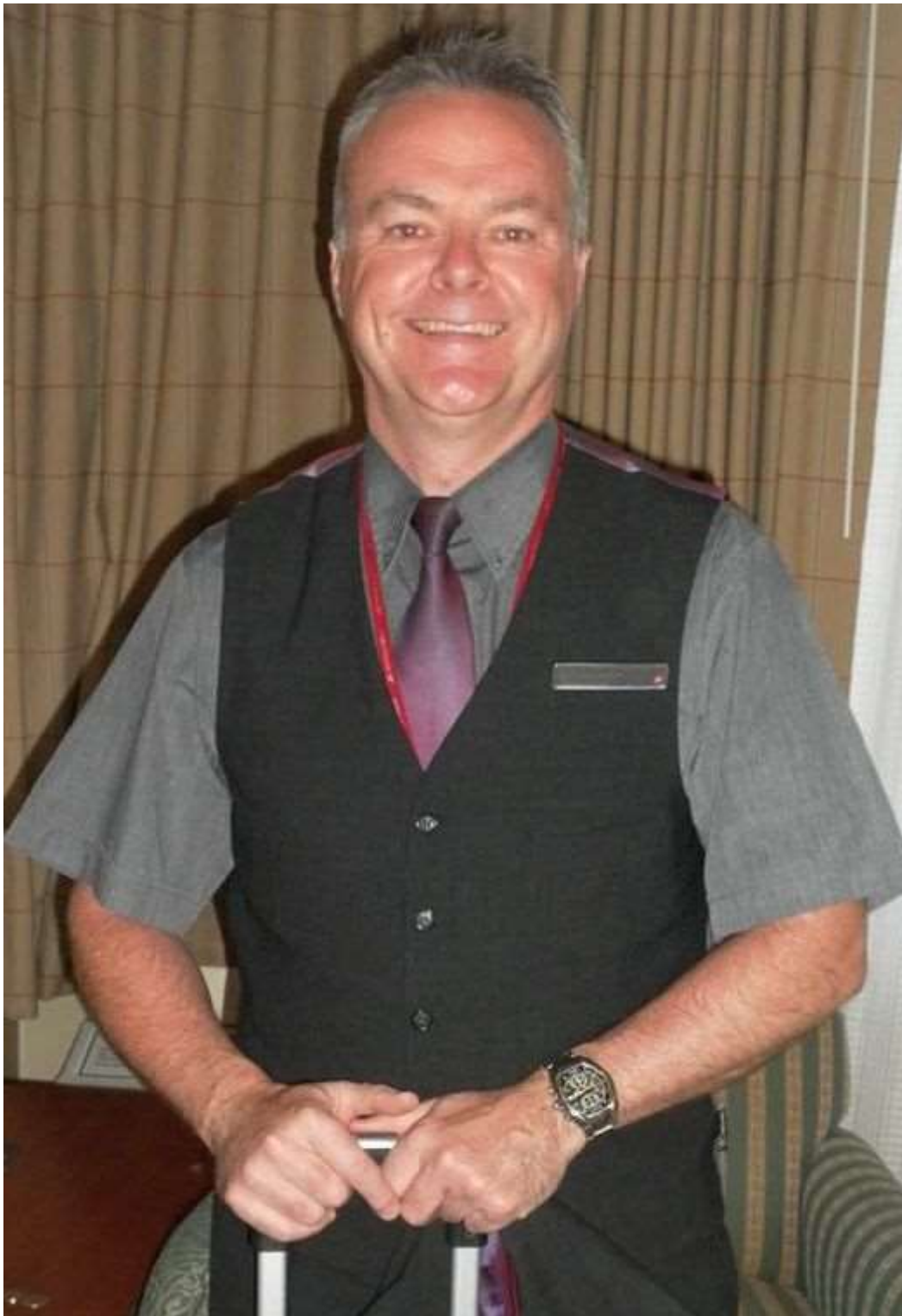
**Cause of leak: Instrumentation Puncture**

**Date of Onset: May, 2009**

**Diagnostic Tests: Myleogram, CT Guided Myleogram**

**Treatments: Indomethocin, Gabapentin, Blind Blood Patches, Caffeine Infusion**

Hello, my name is Peter Marnick and I am one of the Trustees and Treasurer for the CSF Leak Association. I'd like to give you a brief history of my leak story to date and how I am currently.



My leaker journey started in 2009 after two road traffic accidents within the space of two years. I was side impacted by one and had a rear shunt by another. I was referred to an orthopaedic surgeon who confirmed that disc degeneration had occurred at L4 L5 S1 of the spinal column. Relatively soon after this I started to get left sided sciatica and was referred to a pain management consultant. After conservative methods didn't help, I had a course of steroid injections and physiotherapy to try and release the nerves that were being pinched by the lumbar spine discs. The longest period of time that offered any kind of long-term relief was about four months. During this time I was still trying to hold down a job as a Flight Service Manager for Virgin Atlantic Airways. It was about a year to the date of the accident that I was flying to South Africa walking through the cabin when my back gave way. I was stretchered off and flown back via an air ambulance to Sheffield and then transferred to a private hospital. The procedure to perform a spinal fusion laminectomy was discussed as the only option. I was operated on and spent the best

part of 6 weeks in hospital.

Arriving home, I was faced with many challenges and had to adapt my lifestyle accordingly. Around four days after being home I started to feel unwell. Every time I stood up, I felt sick and had this huge rush of pressure that felt like someone was dragging my brain south. I couldn't eat for fear of being sick and no amount of pain medication helped. I remember an emergency doctor coming to look at me at home and saw this huge bulge at the site of the operation. You are leaking spinal fluid he said. You need to go right now and get that patched. About four hours later I was in another hospital in Sheffield about to have my first blood patch with fibrin glue. It worked for about three days and was then repeated. I subsequently contracted an infection from the procedure so was opened up again whilst they realigned the screw that had punctured my dura causing the leak.

About four years later and after being relatively symptom free, I started to get headaches when upright. Initially just one or two, then three, four, five a week. Then it was all the time. They diagnosed it as migraine. About one year later in 2013 I was referred to a neurologist. *It's new daily persistent headache*, I was told within about twenty minutes of seeing him. I couldn't have been happier and took the prescribed tablets, Nortriptyline (No Change), Indomethacin (No Change).

Having now been treated by three neurologists it is believed this is a slow leak and one that has not been picked up on any scan. I sometimes spend days in bed but I am what we refer to as a functional leaker. I had to leave my previous flying career of 28 years because of the problems with pressure. I am now trying to hold down a job as a Customer Experience Manager for East Midlands Trains. It's proving challenging and I have to make lifestyle changes, but I'm grateful that I can at least feel like I have a purpose. I am also very proud to have been a Trustee of the charity since its inception, apart from a short period, for some personal time away. I am determined that we as a charity will make a difference and value your membership to allow us to continue to do so.



The CSF Leak Association was delighted to be invited to endorse and attend the first Headache Academy, a teaching weekend on headache disorders which was held on the 13<sup>th</sup>-14<sup>th</sup> October 2018 at the Royal College of Physicians in London. The foremost headache experts in the country were invited to speak and give case presentations.

The aim of the weekend was to help clinicians to



- Learn how to diagnose major categories of headache accurately
- Manage headache disorders more effectively
- Understand the evidence base for currently available treatments
- Develop effective, individualised treatment plans for patients.

In attendance were 140 delegates made up of Specialist Registrars in Neurology, Paediatrics, Emergency Medicine and General Practice along with Headache Specialist Nurses and researchers. It was a first for the charity. Fellow trustee Clare Joy and I had no idea what to expect as we set up our stand. From the moment the doors opened we were busy engaging with delegates wanting to find out more about CSF leaks. We soon had to replenish the supplies of leaflets and factsheets which had been handed out to keen recipients wanting them for patients or to display on hospital walls. When the delegates moved into the lecture theatre we were able to introduce ourselves to the other charities present.

It was a pleasure to meet Clare Parr and Shelly Williamson representatives from Idiopathic Intracranial Hypotension (IIH) UK and Jillie Abbott and Michèle Welborn from the Trigeminal Neuralgia Association (TNA) UK. Like us they themselves suffer with the conditions they represent or have family members affected by the conditions so we had a lot in common. They were very generous with the advice they shared and we will maintain the links we made and work with them for the benefit of all our members and supporters who also live with or have experience of IIH and TN.



*Left: Dr Gemma Pearce and Trustee Clare Joy*  
*Right: Our Trustees Clare Sargeant and Clare Joy, and Michele Welborn (TNA UK)*

Trustees Clare Sargeant and Clare Joy attended on behalf of the Association. Here is Clare Sargeant's summary of the day.

The weekend had a packed programme so we had to plan our up/down time carefully as we had particular interest in attending some talks in which CSF leaks were discussed. That being said, we still tried to listen to as many talks as we could and throughout the weekend I was struck by the challenges involved in making a correct diagnosis for each headache type – a thorough history taking seemed as important as choosing the right type of test or scan. Lots of time was spent discussing the variety of medications and interventions available to clinicians with reference to the evidence base for each and one talk spent some time on Medication

Overuse Headache which was very interesting as the speaker discussed the benefits of withdrawing medication (easier said than done!).

During one of the breaks we were delighted to be approached by Victoria Quarshie (Headache Nurse Specialist) and Dr Fayyaz Ahmed (Consultant Neurologist, Hull and East Yorkshire Hospitals) who invited us to attend the British Association of the Study of Headache (BASH) National Meeting on Headache in Hull on 17<sup>th</sup> – 18<sup>th</sup> January 2019. Dr Brendan Davies (Consultant Neurologist, Royal Stoke University Hospital) who is a member of our Medical Advisory Committee is giving a presentation on CSF leaks at this event so we will definitely be there and we look forward to it immensely!

We also had the pleasure of meeting Dr Gemma Pearce, a researcher with an interest in Ehlers Danlos Syndrome, who took on the slightly mammoth task of distilling some of the key messages from the weekend for sharing on twitter.

Specifically CSF leaks were discussed during a few talks over the two days:

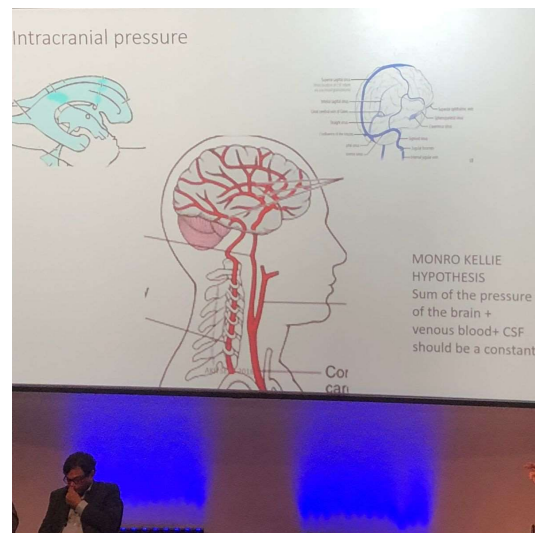
- Dr Jane Anderson (Consultant Neurologist, Addenbrooke's Hospital Cambridge) outlined the difference between primary headache disorders, e.g. migraine, and secondary headache disorders, e.g. spontaneous intracranial hypotension and idiopathic intracranial hypertension. She gave a good run down of all the different types of secondary headache, including two slides on leaks.
- Dr Alok Tyagi (Consultant Neurologist, Queen Elizabeth Hospital Glasgow) discussed a series of case studies, one of which concerned a patient who experienced a thunderclap headache that proved not to be a subarachnoid haemorrhage as originally suspected. In fact, after multiple weeks and further imaging the patient was diagnosed as having spontaneous intracranial hypotension. The need to listen to the patient's 'convincing story' of postural headache was stressed to the delegates.
- Dr Callum Duncan (Consultant Neurologist, Aberdeen Royal Infirmary) gave a very interesting case presentation of a patient who appeared at first to have classic symptoms of a leak, i.e. a postural headache which improved when lying down. After further investigation however, it was discovered the patient had a positional headache caused by occipital condyle syndrome. The patient's headache only improved when lying down on his left side rather than lying down in any position. We found this fascinating as we had never heard of this syndrome before and it keenly highlighted the difficulties of differentiating between headache types and the difference a curious doctor who perseveres can make to the patient.
- Dr Manjit Matharu (Consultant Neurologist, National Hospital for Neurology and Neurosurgery) gave the most interesting presentation of the weekend for us which was solely about spinal CSF leaks. He began by listing different causes of orthostatic headache these being:

1. Decreased CSF production (not proven)
2. Increased CSF absorption (not proven)
3. A CSF Leak
4. Postural Orthostatic Tachycardia Syndrome (PoTS)
5. Cervicogenic headache
6. Occipital condyle syndrome
7. Migraine (feels better if you don't move about)

- Dr Matharu noted the association spinal leaks have with Ehlers Danlos Syndrome and went on to outline the abnormalities to look out for in a brain MRI, stating that 20% of CSF leak patients have a normal MRI brain scan. He went on to say that if the leak site is found on the scan and a targeted epidural blood patch is given there is an 87% success rate. If there is evidence of a leak but the leak site is unknown then the chances of success reduce to 36-57%. For those whose blood patch did not work first time round it was suggested to try two more times. Dr Matharu then asked Dr Tyagi to comment and they discussed the uncertainties in diagnosis and difficulties in managing a CSF leak when conservative measures and epidural blood patches fail to resolve symptoms. They both favoured trying a conservative approach initially as they noted that symptoms can worsen after blood patch, lumbar puncture or CT myelogram. The majority of CSF leaks resolve spontaneously with bed rest and hydration with abdominal binders and caffeine infusions often tried. Both agreed that CSF leaks are more prevalent than currently believed and that there was a need for a study to look at the natural history of CSF leaks (what would happen with no interventions) as well as a patient registry for greater understanding of the condition.

It was an exhausting weekend but well worth the effort. I came away feeling optimistic that a new generation of doctors would return to their hospitals and surgeries better equipped to recognise, diagnose and treat CSF leak patients and pass this knowledge on to their colleagues. I dare to hope that in time it will be recognised that CSF leaks are not so rare after all; that all patients will be diagnosed and treated quickly and effectively, able to return to their normal lives as soon as possible. Until that day comes we will continue to work to achieve this aim.

The Headache Academy was a great opportunity to raise awareness of our charity, the work we do and the patients we represent. Many thanks to Dr. Matharu for inviting us and for his continuing support on the Medical Advisory Committee.





In this edition we get to know Medical Advisory Committee member, Dr. Anthony Ordman a little better, and in particular, what drew him to join the MAC.

*I was delighted to be asked to become a member of the Medical Advisory Board for the CSF Leak Association. As an anaesthetist, who had moved sideways into becoming a full-time pain specialist at the Royal Free Hospital's Pain Clinic in London, I felt that I had a good skill mix to help people suffering from CSF leak symptoms who were contemplating undergoing a series of epidural blood patches. I felt so sorry for those whose lives were interrupted and on hold by their low-pressure symptoms.*

*As a pain specialist, I enjoyed seeing our patients in clinic, spending time discussing epidural blood patches with each person, before starting their series of epidural blood patches, often seeing them between each procedure to check on progress. I really enjoyed working with people in this way, and have formed one or two lasting associations with them, via the CSF Leak Association.*

*I developed a routine for carrying out epidural blood patches that optimised safety for patients, and the chances of improvement. This involved carrying out the procedures in the operating theatre, with light sedation available, using biplanar x-ray screening to ensure optimal epidural needle placement before blood was injected into the epidural space.*

*I carried out a series of epidural blood patches for Dr Matharu's patients. He and I then presented this series at a neurology meeting, and our combined audit showed that despite the relatively longstanding cases we had treated with blood patches, our success rate in improving symptoms was very good, probably second best in the country.*

*We had little trouble in obtaining insurance cover for those patients who had the benefit of private insurance and wished to be treated privately.*

*I am hoping that through the CSF Leak Association I will be able to share advice on the practice of the autologous blood patch for maximum safety and benefit. Meanwhile, I continue to learn from my specialist colleagues in the Medical Advisory Committee, and equally from the expert patients who make up the Trustees of the Association.*

We thank Dr. Ordman very much indeed for taking the time to write this piece for the newsletter.





## AIMS AND OBJECTIVES

- △ Promote **awareness** of Cerebrospinal Fluid Leaks
- △ Improve **information** relating to the causes, symptoms, diagnosis, and treatment of CSF leaks
- △ Advance **understanding** of the causes, symptoms, diagnosis and treatment of CSF leaks

📌 **Campaign** for positive change in health care provision for people suffering from CSF leaks

📌 Improve **availability** of investigatory tests and treatments for people suffering from CSF leaks

📌 Encourage and support **research** into CSF leaks

## WORK TO DATE

📌 Established the **charity** in 2016

📌 Established a **Medical Advisory Committee**

📌 Improved and added to our **website**

📌 **Published** new overview leaflets with input from top UK neurologists

📌 Reviewed and updated **factsheets**

📌 Created an online database of CSF leak journal **articles**, with direct links to PubMed/PMC etc.

📌 Worked with other **organisations** including the Spinal CSF Leak Foundation, and the Brain and Spine Foundation

📌 Reviewed and updated an online searchable **database** of doctors with experience of CSF leaks

📌 Improved access to diagnostic techniques and **treatment**

📌 Published an Android App for use on **mobile** devices

📌 Worked with bodies such as **Orphanet**, EDS, the Brain and Spine Foundation and Inspire CSF Leak Support forum

📌 Established the newsletter '**Leaker Life**'

📌 Prepared and adopted a range of **policies** and protocols

📌 Supported **awareness** and fundraising events

📌 Opened for **membership**

📌 This work has provided us with a solid base to take the work of the charity **forward**

## MOVING FORWARD

📌 Work with the **Medical Advisory Committee** to:

📌 Create a **patient pathway** to give CSF leak sufferers quick diagnosis and treatment

- 🔹 Form research **partnerships**
- 🔹 Promote **research** into the frequency, causes, diagnosis and treatment of CSF leaks
- 🔹 Continue to increase **awareness** of CSF leaks
- 🔹 Expand our **links** with related charities, businesses and government bodies
- 🔹 Refresh our **website** and increase user resources
- 🔹 Expand our range of **factsheets and leaflets** ensuring accuracy
- 🔹 Improve access to **diagnostic** techniques and treatment
- 🔹 Create a '**toolkit**' for GPs to assist in recognising a CSF leak
- 🔹 Expand **outreach** work with other bodies
- 🔹 Continue **support** for awareness and fundraising events
- 🔹 **grow** our membership, volunteers and trustees
- 🔹 Ensure our work **delivers** on our aims and objectives

#### CSF Leak Association

Working to raise awareness of CSF leaks, support research and improve access to diagnostic tests and treatments



The CSF Leak Association has teamed up with DontSendMeACard.com so that you can send customised e-cards and donate the equivalent costs of buying and sending the cards to charity. In addition you can post your Christmas greeting to Facebook or Twitter and spread our message of awareness even further...and if you're a UK taxpayer, you can even use Gift Aid!

Please click [here](#) to visit the Don't Send Me a Card page.

In addition to the generic e-cards, we created our own festive cards for the Christmas season with a little photographic help from member and fellow CSF leaker, Kariina Pirhonen. The good news keeps coming though, as this platform can be used for a variety of occasions or festivals throughout the year and we'd love to receive submissions from our membership for other occasions, even those not currently listed on the platform. Please get in touch if you're interested in helping out.



For a treat over the Christmas period, here are some ideas for Coffee Cocktails. It goes without saying to go easy on the alcohol if you're leaking and keep well rehydrated... or opt for the scrummy non alcoholic cocktail!

### **Irish coffee cocktail**

- 40 ml Irish whiskey
- 2 tsp Brown sugar
- Hot brewed coffee
- Whipped cream

Fill Irish coffee cup with hot water, let sit for 2 minutes, then discard the water. Add the whiskey and sugar to the glass, fill with coffee and stir. Top with whipped cream.



### **Dark & stormy coffee cocktail**

- 25ml Dark rum
- 25ml Tequila
- Ice
- Ginger beer
- 2 Tbsp freshly brewed espresso

Fill a highball glass with ice and pour in the rum and tequila. Stir, then top ginger beer then slowly pour in the espresso.



### **Espresso martini**

- 30 ml freshly brewed espresso
- 50ml Vodka
- 25ml Baileys

Freeze the espresso in an ice cube tray until frozen solid. Pour the vodka and baileys into a tumbler with ice. Add 4-5 coffee ice cubes into the drink and serve.

### **Kahlua coffee cream**

- 300ml strong coffee, cooled

- 50 ml Kahlua
- Sugar to taste
- 2 Tbsp double cream
- Cocoa powder for dusting

Mix the coffee and Kahlua in a wine glass.

Slowly pour in the double cream over the back of a teaspoon so that it gently settles on the top of the coffee.

Dust with a little cocoa and serve.

### Coffee Cola Cocktail (non alcoholic)

In a tumbler

100ml strong coffee

200 ml cherry cola

top with whipped cream and sprinkle with cinnamon

ENJOY!





### 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**

### Spread the word!

If you enjoyed this newsletter, why not share it on social media or email it to your friends?



 Share this newsletter on Facebook

 Tweet about this newsletter

 Forward this newsletter to a friend

 Pin this newsletter to your board



The CSF Leak Association is a member of the [Scottish Council for Voluntary Organisations](#).

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