

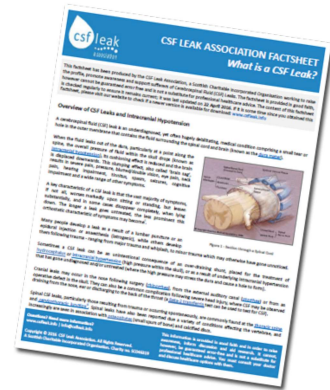


## Message from the Chairman

Dear <<First Name>>. Welcome to the second edition of 'Leaker Life', the quarterly e-newsletter published by the CSF Leak Association. We are a UK charity working to raise the profile of cerebrospinal fluid (CSF) leaks and support improved access to the very best investigatory techniques and treatment for this often debilitating condition.

Our last newsletter, published in summer 2016, was our first. We received a lot of positive feedback, as well as some well-considered and extremely useful suggestions for future editions and content. As a result, we have decided to publish on a quarterly basis, rather than twice yearly, and in due course articles will also be accessible via our website. We hope that this will make the Leaker Life easy to digest and able to respond to news and events as they unfold.

Aside from newsletter preparation, a lot of hard work and progress has been going on behind the scenes since our last edition. We have formally partnered with the US Spinal CSF Leak Foundation to co-manage the Inspire Spinal CSF Leak Community, we have concluded the lion's share of the red tape applicable to all new charities and we have started to put in place the foundations for a Medical Advisory Board, which we hope will eventually



## CSF Leak Factsheets

Our website provides links to a number of useful factsheets. Most have been produced by us, while some others have been produced by organisations such as the NHS or the Spinal CSF Leak Foundation in the USA.

We have begun work on additional factsheets endorsed by UK doctors, which we hope will assist patients and doctors in both diagnosis and treatment of CSF Leaks. [Learn more](#)



comprise medical professionals from across the UK.

When originally formed, the CSF Leak Association was overseen by six trustees - five being CSF leakers - hailing from around the UK. We remain very much a grassroots organisation, run by leakers for leakers, with big aspirations; while we have made significant progress already, we also know that change takes time and there is much work to do with many roles requiring to be filled.

With this in mind, we are very pleased to announce that Polly Walker has now joined the board. Polly is passionate about improving the quality and range of support and treatment options available to CSF leak sufferers in the UK. She is a fantastic addition to the Trustee team and brings with her a wealth of experience from her work in education, mediation and publishing – welcome, Polly!

As ever, we welcome all with ideas for content, or any other suggestions, to get in contact with us to help make future editions even better. For those of you who are new to us, we hope that you will enjoy this edition and return again, and for those who are existing subscribers, thank you for your continuing support.

David Baldwin  
Chairman



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](http://www.spinalcsfleak.inspire.com)



Cerebrospinal Fluid (CSF) surrounds our brains and spinal cord, and protects our brains by keeping them in a cushioned or buoyant state. The fluid is held in place, thus maintaining the pressure and volume around our brains, by three layers of membrane called the meninges. The outer, toughest membrane is

called the Dura Mater (or dura, for short). Imagine this as a large balloon, holding the fluid securely in place with our brains and spinal cords inside.

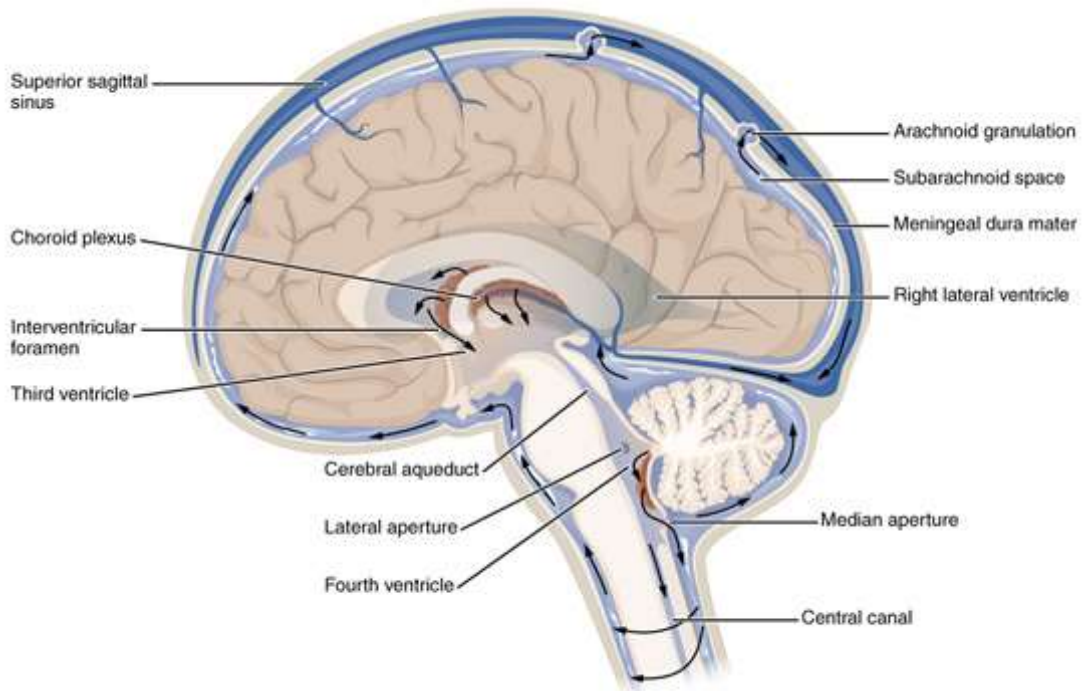


Figure: *Anatomy of the brain and spinal cord.*

Image: OpenStax / Wikipedia

CSF can leak out when the dura is opened in some way – e.g. pierced, torn or has ruptured - and this often results in a condition called Intracranial Hypotension: when there is a low volume of CSF or pressure in the head, and the brain becomes displaced downward. In other words, the brain sags inside the skull and sits lower than it should do, where it begins to come into contact with the cranial nerves and cause a number of symptoms that can range from subtle and nagging to completely debilitating.

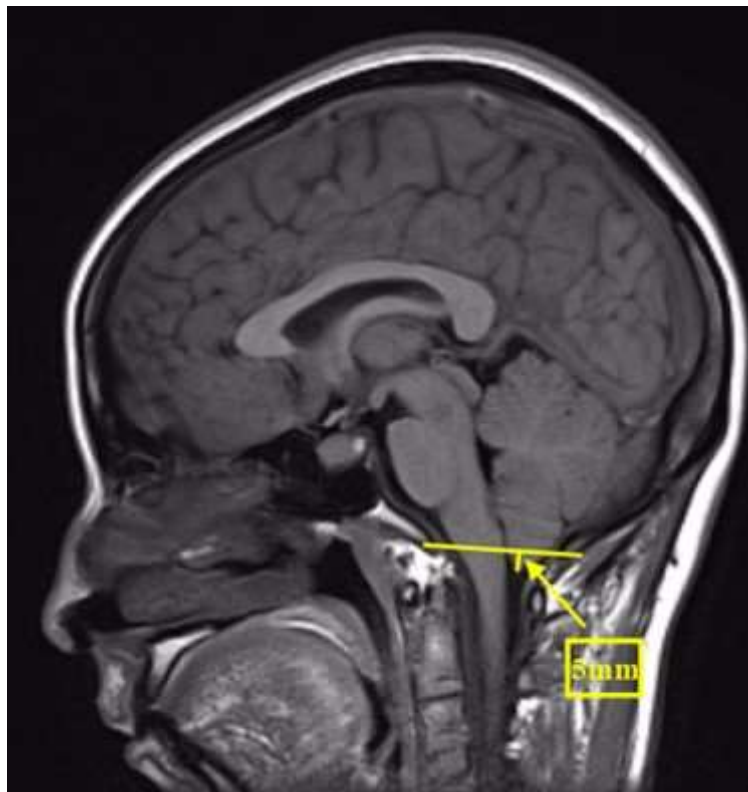


Figure: *MRI Scan showing 'brain sag', typical of intracranial hypotension.*

Image: PLoS One. 2015; 10(4): e0123616 (Creative Commons Licence)

## Symptoms of Intracranial Hypotension

The most common symptom is a severe headache that is only relieved by lying down (thus enabling the brain to return to its usual position, and away from nerve sensitive structures). Other symptoms can include the following, but they can present themselves in varying combinations and to different levels of severity, but for many, the only way to gain any relief is to spend most of their day lying flat. Sitting up is so excruciating that it makes daily tasks impossible.

### Head

- Headaches (frontal, parietal and occipital)
- Heaviness of head
- Feeling of pressure within the head
- Sensitivity of, or tingling sensations within, the scalp

### Ears/Hearing

- Tinnitus (ranging from ringing and buzzing to pulsatile tinnitus)
- Pressure sensations in the ears/ear popping
- Feeling of liquid in the ears
- Hearing loss (sometimes similar to Meniere's disease) and dulled hearing

### Eyes/Vision

- Blurry vision
- Double vision
- Pain behind eyes
- Pain when moving eyes

### Facial

- Facial numbness
- Sinus pressure
- Jaw pain/tooth ache
- Temporomandibular joint pain and stiffness

### Back, Neck & Limbs

- Neck pain and stiffness
- Back pain (area-specific and general)
- Tingling sensations and spasms in the spine, back, arms and sometimes legs

### Other Symptoms

- Rapid heartbeat, particularly when sitting or standing
- Nausea and, in extreme cases, sickness
- Cognitive impairment and decline (including memory loss and loss of concentration)

## Causes of Intracranial Hypotension

There are several situations that can lead to the development of Intracranial Hypotension (low CSF volume / pressure in the head). This is almost always secondary to a spinal CSF leak. There are three main categories:

1. **Iatrogenic** – caused by a medical procedure intentionally or inadvertently.

(a) Post lumbar puncture CSF leak (often known as Post Dural Puncture Headache or PDPH) this is the most common cause of a spinal CSF leak. The lumbar Dura is intentionally punctured for various diagnostic and therapeutic reasons. An example would be a diagnostic lumbar puncture (LP) for a patient thought to have meningitis, to analyse and culture the cerebrospinal fluid. Another would be a lumbar puncture for injection of contrast for a type of spinal imaging known as myelography. A common

therapeutic reason would be spinal anaesthesia. Most often these holes heal over quickly, but in some cases, they do not. It is not yet common practice to use a less traumatic type of LP needle (pencil-tip vs. sharp), even though these reduce the risk of post-LP headache substantially.



Figure: Lumbar puncture procedure

Image: Brainhell - Wikipedia, CC BY-SA 3.0

- (b) Dural tears may occur inadvertently at the time of epidural injections. (Epidural space is in spinal canal outside of dura and spinal cord)
- (c) They may occur at the time of surgery.
- (d) CSF shunt over-drainage may cause intracranial hypotension.

## 2. **Traumatic** – caused as a result of an injury.

Traumatic leaks have been reported in association with whiplash, brachial plexus injuries, spinal injuries, sports injuries, falls and chiropractic neck manipulation.

## 3. **Spontaneous** – occurring with minimal or no clear precipitant.

Spontaneous spinal CSF leaks may arise with or without obvious precipitant. Common reported events or mechanical factors associated with the onset of symptoms include lifting small or large items, straining, stretching, positional changes, sporting activities, roller coaster rides and falls. Some of these might be categorised as traumatic.

- (a) Spontaneous spinal CSF leaks may be associated with spinal pathology such as calcified disc material or bone spurs. These leaks are often ventral or anterior to the spinal cord.



Figure: Bone spurs (osteophytes) can form at calcified discs and within the spinal canal. Depending on their form and location, they are a known cause of CSF leak.

- (b) There is a growing evidence base suggesting that a significant proportion of spontaneous spinal CSF leaks occur as a result of pre-existing dural weakness. A range of dural defects have been reported at surgery. Electron microscopy of dura has revealed abnormalities in a substantial proportion of cases. Heritable Disorders of Connective Tissue occur at a higher frequency in affected individuals; intracranial hypotension may be the first noted manifestation. Marfan syndrome, Ehlers Danlos syndrome (both classic and hypermobility type) and unspecified heritable disorders of connective tissue have been reported. Patients with spontaneous spinal CSF leaks have been shown to have higher risk of intracranial aneurysms, bicuspid aortic valve and thoracic aortic aneurysms and should be evaluated for Heritable Disorders of Connective Tissue.

Please also check out our easy-read factsheet and share it with as many people as you can: [www.csfleak.info/downloads/download-info/what-is-a-csf-leak-factsheet](http://www.csfleak.info/downloads/download-info/what-is-a-csf-leak-factsheet)

**Sources:** Various, but with particular thanks to the [Spinal CSF Leak Foundation](http://www.spinalcsfleakfoundation.org) upon whose advice note much of this article is, with permission, based.

**NB.** Cranial CSF Leaks often present with different symptoms to leaks at the level of the spine and will be covered in a separate 'Focus' article in due course.



In this spotlight section we take a brief look at notable journal articles and research relevant to CSF Leaks and Intracranial Hypotension. Some may be new publications, while others may be well-established, important papers.

In this edition, we look at two newly published papers, one from Schievink et al. on a new **classification system of spontaneous spinal CSF leaks** in *Neurology: the Official Journal of the American Academy of Neurology* and the other from Amrhein et al. on **CT fluoroscopy-guided blood patching of ventral CSF leaks** in the *American Journal of Neuroradiology*.

Both publications are key and extremely welcome additions to the growing catalogue of medical papers relating CSF leaks and associated conditions, and it is important that they are widely distributed, not least within the NHS. Paid subscriptions are required to view the full text of these papers, however the abstracts do provide a reasonable overview.

The new classifications systems for spinal leaks is of particular importance and will play a crucial part in ensuring that leakers are afforded the correct care and treatment options; as many CSF leak sufferers will be all too aware, CSF leaks are often lumped into one category, with insufficient recognition given to, amongst other things, causation, form and location.

With regard to guided patching for spinal CSF leaks, the team at Duke University in North Carolina have been working at the coalface for many years and are widely held as being leading lights in the field of guided fibrin glue patching, as well as leak detection using dynamic CT Myelography. Patients travel from around the world to visit their centre in Raleigh.

It is not at all uncommon for ventral (also referred to as *anterior*) spinal leaks to fail to respond well to standard epidural blood patches, and often specialised surgery is required. It is therefore both heartening and exciting to see a guided transforaminal approach now being used with success and positive safety profile. We can only hope that this refined technique will be adopted by hospitals in the UK without undue delay.

## A classification system of spontaneous spinal CSF leaks.

Schievink WI, Maya MM, Jean-Pierre S, Nuño M, Prasad RS, Moser FG.

Abstract

### OBJECTIVE

Spontaneous spinal CSF leaks cause spontaneous intracranial hypotension but no systematic study of the different types of these CSF leaks has been reported. Based on our experience with spontaneous intracranial hypotension, we propose a classification system of spontaneous spinal CSF leaks.

### RESULTS

The mean age of the 568 patients (373 [65.7%] women) was 45.7 years. Three types of CSF leak could be identified.

- **Type 1** - CSF leaks consisted of a dural tear (151 patients [26.6%]) and these were almost exclusively associated with an extradural CSF collection.
- **Type 1a** - represented ventral CSF leaks (96%) and **Type 1b** posterolateral CSF leaks (4%).
- **Type 2** - CSF leaks consisted of meningeal diverticula (240 patients [42.3%]) and were the source of an extradural CSF collection in 53 of these patients (22.1%).
- **Type 2a** - represented simple diverticula (90.8%) and **Type 2b** complex meningeal diverticula/dural ectasia (9.2%).
- **Type 3** - CSF leaks consisted of direct CSF-venous fistulas (14 patients [2.5%]) and these were not associated with extradural CSF collections. A total

of 163 patients (28.7%) had an indeterminate type and extradural CSF collections were noted in 84 (51.5%) of these patients.

## CONCLUSIONS

We identified 3 types of spontaneous spinal CSF leak in this observational study: the dural tear, the meningeal diverticulum, and the CSF-venous fistula. These 3 types and the presence or absence of extradural CSF form the basis of a comprehensive classification system.

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**Full article:** <https://www.ncbi.nlm.nih.gov/pubmed/27440149>

## **CT Fluoroscopy-Guided Blood Patching of Ventral CSF Leaks by Direct Needle Placement in the Ventral Epidural Space Using a Transforaminal Approach.**

Amrhein TJ, Befera NT, Gray L, Kranz PG.

### Abstract

#### BACKGROUND AND PURPOSE

Epidural blood patch treatment of spontaneous intracranial hypotension arising from ventral CSF leaks can be difficult secondary to challenges in achieving ventral spread of patching material. The purpose of this study was to determine the technical success rates and safety profile of direct needle placement into the ventral epidural space via a posterior transforaminal approach.

#### MATERIALS AND METHODS

We retrospectively reviewed consecutive CT fluoroscopy-guided epidural blood patches from June 2013 through July 2015. Cases were included if a posterior transforaminal approach was taken to place the needle directly in the ventral epidural space. Rates of technical success (defined as contrast in the spinal canal ventral epidural space) and optimal epidurogram (defined as contrast spreading into or beyond the middle third of the spinal canal ventral epidural space) were determined. Factors influencing these rates were assessed. All complications, inadvertent intravascular injections, and intrathecal punctures were recorded.

#### RESULTS

A total of 72 ventral epidural blood patches were identified; immediate technical success was achieved in 95.8% and an optimal epidurogram in 47.2%. Needle position within the spinal canal ventral epidural space was associated with obtaining an optimal epidurogram ( $P = .005$ ). Inadvertent intravascular injection was identified in 29.3% of cases, but all were venous. There were no inadvertent intrathecal punctures or complications.

#### CONCLUSIONS

Direct needle placement in the ventral epidural space via a transforaminal approach for treatment of ventral CSF leaks has an excellent technical success rate and



safety profile. This technique can be considered as a treatment option in selected patients with ventral CSF leaks for whom traditional techniques are unsuccessful.

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**Full article:** [www.ncbi.nlm.nih.gov/pubmed/27390315](http://www.ncbi.nlm.nih.gov/pubmed/27390315)



## Slogan Competition

As you may remember, we announced a competition in our Summer 2016 newsletter to help us come up with a slogan which could help us in our quest to raise awareness of CSF leaks. We announced the winners in August 2016, but here's a little reminder...

The judging panel decided to declare two entries joint winner, so congratulations to **Mila Johns** (from the USA) who came up with 'Stop the Brain Drain' and **Andrea Dilley** (from the UK) who proposed 'Let's Get Vertical'.

These are truly excellent slogans and we are very pleased to announce that both of them have been woven into two distinctive logos, which now feature on a range of limited edition clothing, mugs, accessories and gifts available via our online shop.

[Buy T-Shirts](#)

[Buy Mugs & Gifts](#)

## Rogues' Gallery: Autumn 2016



## Leaker Profile: Cameron Goodship (Age 12)

At only four and a half years old, Cameron was diagnosed with papilledema after his optician identified swelling behind his eyes. A lumbar puncture was requested to test his CSF pressure and, following months of delays and insistence from his parents, this was finally carried out. Cameron's pressure reading was dangerously high, and he was placed on Diamox (acetazolamide) immediately, as well as furosemide as diuretics, using the top dose recommended for a child of that age.

Cameron did not respond well to taking Diamox. He was nauseated, tired and could not join in with any

activities that a boy of his age would normally do. He was constantly exhausted and spent a lot of time sleeping and feeling extremely unwell and his quality of life was minimal. As Cameron also suffers with Crohn's Disease, the combinations of medication he required for both conditions interacted with one another and resulted in a horrible combination of side effects. Cameron stopped gaining weight and his heightened CSF pressure was not relieved.

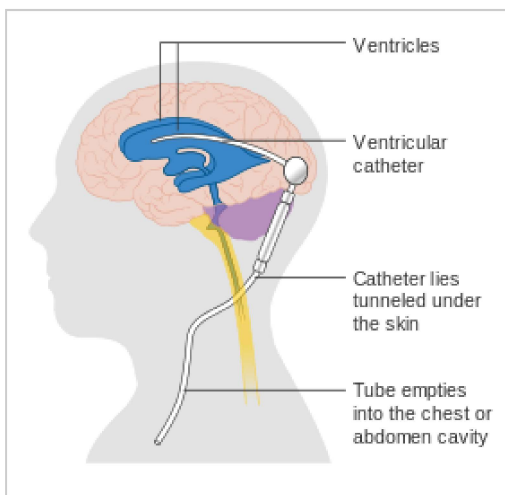
Eventually, the family were referred to a neurosurgeon, but unfortunately the first visit was not a positive one, with the family left reeling when they were told that they weren't sure why they were carrying out the operation: 'He hasn't gone blind yet!'. So the family continued to struggle until finally, at the age of 7, Cameron had a shunt fitted. It was hoped that it would provide as few complications as possible.



After the shunt was fitted, Cameron was very poorly. He went into low pressure many times, suffering the same debilitating symptoms as many a CSF leaker. Cameron reported that he felt like he just wanted to lie down, to shield his eyes from the light and to sleep. Whilst his symptoms were now different to those he experienced with high pressure, he felt much worse at times. It took a long time for his pressure to settle, in any way.

Unfortunately – yet inevitably – Cameron missed a great deal of his schooling. However, he is a bright, inquisitive child and is determined to progress his learning. He was able to catch up the schoolwork he had missed and was able to clearly demonstrate his fascination with some areas of the curriculum to his teachers. His year 3 teacher, in particular was very helpful, and had a greater understanding of the impact of low intracranial pressure due to a relative with the same condition.

Provision was made for Cameron to help him through the school day – he could have time out when required, to retreat to quiet areas or put his head down on the table as and when necessary. Sports Day was a particularly difficult day for Cameron – he recalls the heightened activity and heat causing greater symptoms than usual, which nothing would relieve.



Cameron's friends were sadly less understanding than his teacher. As well as the horrendous physical symptoms caused by low intracranial pressure, Cameron had the additional heartache caused by the unkindness of his school peers, who had a very limited understanding of his condition and what he had been through. They teased him for being different, calling him 'Robot Boy' due to his shunt fitting.

A new teacher was also less understanding, claiming on occasion that Cameron 'Only had a headache'. Thankfully, the head teacher spent time sensitively raising the awareness of Cameron's condition that was so desperately lacking, bringing about a shift in attitudes throughout the school and replacing

ignorance with kindness, respect and thoughtful interaction.

As the years have gone by, Cameron has learned to cope with his medical conditions and with school generally, with a maturity not usually seen for his age. Despite missing so much schooling, he has

achieved highly in all areas – even achieving above and beyond all expectations of his year group.

Cameron is a highly intelligent, articulate boy who is learning to cope with all life has thrown at him with an honest, open mind and wonderful resilience. He does not want extra attention, he is not looking for sympathy when he is feeling poorly, he just wants to get on with his life and gain the best quality of life that he is able to.

The shunt has helped, but he still deals with low pressure symptoms with regular frequency and having coped with a total of sixteen lumbar punctures as well as surgery, he is keen to move away from this experience and lead a normal life. Cameron is also very keen to do as much as he can to raise awareness of his condition to help others understand.

He is an inspiration to us all.



The CSF Leak Association has partnered with Easyfundraising, Give as You Live and The Giving Machine. When you sign up with one of these gateways, whenever you shop online through qualifying sites such as eBay, Amazon, Tesco, John Lewis etc., the merchants will give a percentage of what you spent to the CSF Leak Association - it's completely free and doesn't cost you a penny!

If you've not signed up already, you can find out more information by following these links:

- [www.easyfundraising.org.uk/causes/csfleak](http://www.easyfundraising.org.uk/causes/csfleak)
- [www.giveasyoulive.com/charity/csfleakassociation](http://www.giveasyoulive.com/charity/csfleakassociation)
- [www.thegivingmachine.co.uk/beneficiary-portal/view/csf-leak-association](http://www.thegivingmachine.co.uk/beneficiary-portal/view/csf-leak-association)



**Work a plan, not a job.**

We know where we're going; now it's time to work out how to get there...

We are currently recruiting for an additional voluntary trustee, someone who has proven experience in business planning, to come on board specifically as Business Plan Developer.

For more information or to apply, please visit: [www.csfleak.info/work-with-us/business-plan-developer](http://www.csfleak.info/work-with-us/business-plan-developer)



## Becky Hill's Blog

There are handful of bloggers around the globe who write about their experiences of living with a CSF leaks. Becky Hill, a current leaker based in the UK, has been blogging about her life, experiences and perspectives for some time now, but she recently published an excellent post on 'Living with a Spinal CSF Leak'. We are sure that her journey, and the struggles, trials and tribulations experienced along the way, will ring true with leakers the world over.

You can read Becky's blog here:

<https://beckyhillblog.wordpress.com/2016/10/07/living-with-a-spinal-csf-leak>



**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**



## Our New Trustee

In September 2016, we welcomed Polly Walker to the CSF Leak Association Board. Polly is now one of the trustees of the charity, taking the total to seven.

Her background is in education; originally training as a primary school teacher, before transitioning to a career focusing on special educational needs - specifically teaching children and young people that were permanently excluded from their main-stream schools, and later leading a team of primary behaviour support specialists.

During her maternity leave, Polly wrote an illustrated children's book based around self-esteem, identity and diversity, which has since been published.

Like so many leakers, prior to suffering a CSF Leak in 2015, Polly lived a very full and active life. Her leak has forced her to slow life right down, but she is grateful to still able to work as a mediator, helping to resolve disputes between parents, carers, schools and local authorities where a conflict has arisen regarding a child, or young person's special educational needs provision.

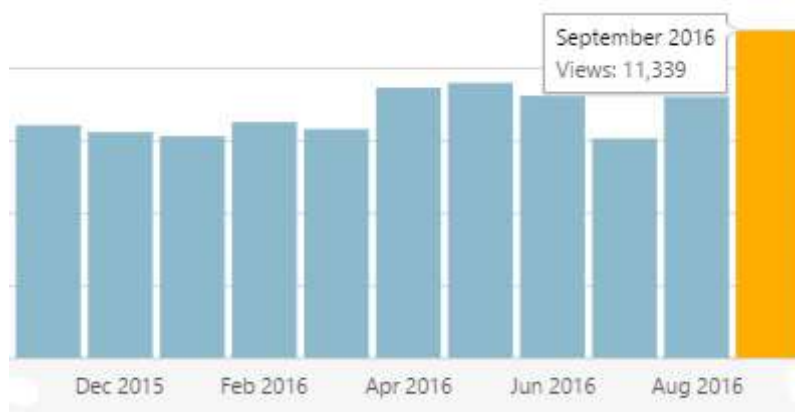
She is passionate about raising awareness of CSF Leaks in a bid to improve the quality of diagnosis and treatment for her fellow 'leakers' and is excited about the future of the charity as it moves from strength to strength.



Polly lives with her husband and two young daughters in Hertfordshire, where she loves to be in the great outdoors as much as possible.

## News Snippets

The charity's website and online presence continues to go from strength-to-strength. We reached an all time high of 11,339 individual hits during September 2016, and have passed 160,000 total individual hits since the site went live in 2014. Website expansion is one of our key goals, so stay tuned for exciting developments.



### Interview with a fundraiser...Kate Hubbard, Tough Mudder!

On the 11th September Kate, Fran and friends took part in the Tough Mudder North West in a bid to raise vital funds for the CSF Leak Association. Here she tells us all about her experience...

#### What made you want to fundraise for the CSF Leak Association?

The CSF Leak Association is a cause very close to home due to my mother suffering from a CSF Leak since December 2009. I have been previously involved with a lot of fundraising for her to receive treatment in America. Over the past year Fran has become a close friend of the family and wanted to help raise as much awareness for the CSF Leak Association as possible.

#### How did you prepare for the Tough Mudder?

Since deciding to take part in Tough Mudder in January, Fran and I have been using our University gym to prepare physically for the event, however I believe that a lot of motivation to get through the course came from each other and our teammates. Altogether, 7 of us completed the event, all fundraising for different charities including Cancer Research and The Motor Neurone Disease Association. Fran and I could not have completed the course without the help from our teammates and vice versa, in addition to helping other teams to overcome the obstacles throughout the course.



### **Which was your favourite obstacle and why?**

Our favourite obstacle of the course had to be the 'Block Ness Monster'. We had to push, pull and roll our way over 60ft of slick, rotating barriers which really tested our teamwork and helping other teams on the course too. We enjoyed this obstacle so much as it was something completely new that we would have not had the chance to do if we didn't take part in Tough Mudder. Although - we both agree that the Arctic Enema 2.0 and Electroshock Therapy were equally as bad!

### **Which was your least favourite obstacle and why?**

Our least favourite obstacle was halfway through the course and it was known as 'Shawshanked'. One by one, we had to make our way backwards up close to vertical pipe using only a rope, and when we got to the top, we had to drop 8ft backwards into a 6ft pool of muddy, cold water then swim out using nets. The worse part was the fall as you can't see where you're falling to and end up disorientated when you finally make your way out from under the water from the fall. To make it worse, this obstacle was about halfway round the course and we had to queue for around 20 minutes when we were already cold and damp, making it very difficult to stay warm to continue running afterwards.

### **What strategies did you have up your sleeve to keep you going through the really tough bits?**

Within our team, we all kept each other going through the really tough parts of the course, particularly when we began to get tired around mile 9 and wanted the end to be in sight! If someone was falling behind, we'd shout as much encouragement as we could to keep them going around the course as we would never leave someone behind, and the whole motto of Tough Mudder is not to finish with a good time, it is



to finish the course together as a team.

### **How did you reward yourselves afterwards?**

After finishing the course, we were rewarded with finishers t-shirt and headband, in addition to a well-earned pint of cider provided by Kingstone Press. On the way home we made a much-needed trip to McDonalds before hosing all the mud off and having a bath to clean up!



### **Do you have any advice for future Tough Mudders?**

Train! Endurance is key to keep running between the obstacles as although you sometimes get breaks between running for the obstacles, you are still physically exhausted from completing the obstacles with your team mates, and then going onto helping other teams on the course too. I wouldn't advise anyone to sign up to complete the course on their own as we all helped each other through.

### **And any messages for your supporters...**

Fran and I would just like to thank everyone who has sponsored us to help raise money for the CSF Leak Association. Although it was a challenge we wanted to complete for ourselves, we were so much more motivated to complete the course with our sponsors in mind. As I said earlier, the CSF Leak is a cause very close to home and we hope to have helped as much as we can by completing the course for the CSF Leak Association.

Kate and Fran's fundraising page can be viewed  
here: <http://www.totalgiving.co.uk/mypage/csfleaktoughmudder>

**Fundraise for us**

Support us through fundraising or a donation

We are a small but active charity that relies heavily on the generosity of our members and the general public to help us raise awareness of debilitating cerebrospinal fluid leaks.

If you have found this newsletter useful or have benefited from our website, factsheets and other resources, please consider lending us your support.

If you would like to make a donation to help us in our work, or you're thinking of doing a sponsored run, parachute jump, bungee jump or other event and you'd like to fundraise for us, we would be very pleased to receive your support.

[Visit our fundraising, donations & volunteering pages](#)



For CSF leak sufferers in the US, the Spinal CSF Leak Foundation is a non-profit health advocacy foundation by individuals affected with spinal CSF leaks. We have recently entered into partnership with them to co-manage the [Inspire Spinal CSF Leak Community](#).

The Foundation was established in June 2014 and is working to expand their efforts in education to both patients and health care professionals, as well as to raise funds for research. With that in mind, they are currently organising the world's first **Intracranial Hypotension Symposium**, to take place in California on 14 October 2017.

Further information on the Spinal CSF Leak Foundation and the symposium can be found at: [www.spinalcsfleak.org/symposium-2017](http://www.spinalcsfleak.org/symposium-2017)





## Spread the word...far and wide.

In order to raise awareness and secure improvements in diagnostic and treatment options that sufferers desperately need and deserve, we need as many people as possible to hear about CSF leaks.

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

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 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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