



Message from the Trustees

Hello, <<First Name>>.

Welcome to the long awaited Spring / Summer edition of Leaker Life.

As always, lots of action has been taking place behind the scenes and the Association continues to make great strides forward. Read on to find out about what we've been up to, events we've attended and newcomers that have joined us.

We're on the look out for interesting fundraisers to feature next time - are you taking part in one? Or would you like to? Contact us if you need some inspiration!

As always, thank you for your ongoing support.

Polly Walker

Volunteer Newsletter Editor





We are delighted to welcome Dr Susan Iacovou to the Board of Trustees. Here is her story.



My life changed on October 2015. I was at Euston Station, London, following a day of successful but exhausting meetings. The first sign that something was seriously wrong came when I couldn't eat the bar of chocolate bought to enjoy on the train. Instead of experiencing the usual melt in the mouth moment, I found myself strangely disgusted by the cloying texture and sickly taste. I didn't realise it at the time, but that was the last piece of chocolate (indeed the last sweet thing) I would eat to this day, and that moment marked the beginning of a

CSF leak journey that is now in its fourth year.

Travelling home I battled waves of nausea, a neck and head ache like no other and stabbing back pain. I became convinced I'd pulled a muscle, was suffering from travel sickness or had contracted some strange bug. Things worsened over the next 48 hours to the point where severe pain in the back of my head meant I could not be upright and I was admitted to hospital. Four days later, after a seemingly endless round of examinations, blood tests, CT scans and lumbar punctures, doctors concluded that I was suffering from stress.

Over the next month I battled what I now know are classic CSF low pressure symptoms – postural headache, brain fog, neck and shoulder pain, nausea, dizziness, changes in hearing, vision and taste - before an MRI scan conducted privately and out of desperation highlighted the extradural pools of CSF fluid around my brain and the full length of my spinal cord, along with brain sag and all the other neurological signs of a CSF leak. In many ways I was lucky. My leak was obvious enough to show up using a relatively conventional diagnostic scan. Many of my fellow leakers are not so fortunate and face months or even years of non or mis diagnoses.

This is why the CSF Leak Association and its work is so important. In the months that followed my diagnosis I came to rely heavily on the information on the Association website as I sought to understand my condition and find the right doctors to help me. As most readers of this newsletter will know, CSF Leakers often have to become experts in their own condition. I have routinely referred family, friends and doctors (yes, even neurologists) to the research gathered on the CSF Association site. Without this information I would have faced a lack of understanding from those around me and from medical professionals. As my condition has improved (it has now plateaued and I can anticipate and manage the symptoms), I realise how the support and encouragement I received from fellow leakers in the Association Facebook group kept me going through the darkest of days.

Of course the CSF Leak Association charity can't run itself. The webpages I found crucial as I sought to comprehend my experience need to be built and maintained. The Association's social media presence grows only as a result of hard work. The Medical Advisory Committee that does so much to further awareness of the condition needs to be administered and managed. Research papers have to be reviewed and collated. And of course, the Newsletter you are reading right now needs to be written, edited and presented.

All this work is carried out by a small team of dedicated volunteers. Recently I decided to join this band of leak sufferers, healed leakers and family and friends of leakers by taking up the roles of Volunteer Manager and Trustee. Deciding to volunteer was easy. If the Charity did not exist, I would not be where I am now. In some very dark times, the volunteers and the work they did, provided me with vital answers and timely and informed support.

Recently my nephew was totally incapacitated by a CSF leak resulting from a back operation. I was able to point him and his family towards the right resources and they were able to advocate for themselves and receive a blood patch despite initial resistance from doctors lacking experience with the condition. The blood patch worked and he recently wrote these words to me:

'I really wanted to say the biggest ever thank you for all you did helping me

when I was literally at the worst I had ever been in my life. Before my surgery I had never even heard of CSF let alone a CSF leak. I really mean this when I say it, you will never know how much you helped me.'

His heartfelt thankyou brought me to tears. The real thank you however belongs to the CSF Leak Association and the work they do to help hundreds of people with this condition. Without them I would not have been able to help my nephew. For me at least, knowing what both he and I experienced and having read people's stories on Facebook, volunteering becomes a no-brainer (I'm sure you will excuse the pun!).

If you would like to volunteer with the CSF Leak Association, please email me on susan.iacovou@csfleak.info Even if you can only manage half an hour a month, there are suitable tasks that need to be done. One off volunteering with things like website design or focus groups is also welcome. And if you can't volunteer, maybe a friend or family member would like to help out. I hope to hear from you.



Valerie McCluskie is one of our hard working and dedicated volunteers. She has kindly agreed to share the experiences that drew her to the Association, and a little about what her role involves. Thank you, Valerie!



Hi my name is Valerie McCluskie and I am the volunteer Membership Secretary for the CSF Leak Association.

Where?

I live in Easter Ross in the Scottish Highlands with my partner, dog and two cats. We all love the outside and Easter Ross is a beautiful part of the world where we are lucky enough to have access to quiet hills, woods, beaches, trails and wide open sky.

Interests?

I love reading and running with my dog Daisy cross country and through woods from home. Yoga and mindfulness are other passions. I also am really looking forward to travelling around in my partner's classic Albion lorry which he is currently rebuilding!

Why support the CSF Leak Association?

I became aware of the charity from its inception with two friends who are founder members. I have seen first hand how the condition affects individuals and their family and friends. I wanted to be able to help in a constructive way and was able to volunteer a few hours a week.

What does my role involve?

I coordinate the membership application system and posting of membership packs and information to members all around the world. I have had some lovely email conversations with people from as far apart as UK, Norway, USA and Australia! I love to think that the information which the association sends out both over the web and by post is helping people from every possible background, who share CSF Leak as a common issue or interest.

Favourite Book(s)

Dracula for some influential and absolutely classic suspense and language, Errol Le Cain's fairy tales for some beautiful art, and the Robin Hobb series for dragons and mysticism!

Favourite Music
Anything by JJ Cale, the soundtrack of my life.



A huge thank you from us all at the CSF Leak Association to Claire Comley, who shares her cranial leak story in this edition of Leaker Life.



I am a Mum to two young boys, aged eleven and seven and having danced all my life, have always been a very fit and active person.

In May 2014, with my sons aged seven and three, I was hit in the face in a freak accident and apart from the black eye and a lump on my eyebrow which lasted about a year, I didn't think anything of it. Doctors have always maintained that this accident had nothing to do with my leak due to the timings, but as I now know that cranial leaks can start with a head injury, I can't ignore the coincidence.

By July 2014, I had a stiff neck and could not move my head to the right at all. I put this down to our chaotic sleeping arrangements dealing with a toddler who never slept. I had the stiff neck as a symptom for about two years in total.

In September 2014, the headaches started. They weren't "normal" headaches, more a feeling of "interior skull pressure", concentrated on the back and sides of my head. Like a feeling my skull was being crushed at the sides or my head was being pulled backwards. I quickly went downhill and saw the GP three times with no success – diagnosed with tension headache. By October, I was incapacitated every day and rolling around on the floor screaming in agony, unable to function or to sleep. I began vomiting on waking and would vomit for several hours before the pain would settle a little, although I was barely functioning with the intensity of the symptoms.

I then saw a trainee GP who, baffled by what to do with me and thankfully wanted to do everything by the book, fast tracked me to see a neurologist as I now matched all the symptoms of a brain tumour. The neurologist said it was tension headaches, and only ordered an MRI scan because I had excessive plantar reflexes and was positive for Factor V Leiden (a blood disorder completely unconnected to the leak). He called me late at night after my MRI to casually tell me that I had a CSF leak and that such leaks were usually a result of a tumour and that I would need a full head and spine scan the next day. With two young children, the bottom fell out of my world at that news but, in all honesty, I already knew I was gravely ill from the symptoms. (Interestingly, for those struggling with diagnoses and for scans to be read – I could clearly see on my scan pictures, two definite and large sacs of fluid on either side of the top of my brain – two subdural hygromas. There was no doubt of a leak.)

Whilst waiting for the scan, new symptoms developed: Rushes of fluid (tasting like licking a battery) into my throat, horrendous tinnitus like a helicopter whirring not just ringing, aphasia (I had trouble remembering words and speaking), tingling and numbness in my right arm and a feeling of compression across my throat.

At this stage the Neurologist decided I had low pressure from a spinal leak despite me explaining many times the fact that I never had an upright or orthostatic headache. I was lucky my neurologist had some knowledge of CSF leaks but I felt he was hoping that by identifying that it was low pressure and to simply to lie flat, it would go away. My 2nd MRI could not locate the spinal leak they were looking for and so I was advised to lie flat, take caffeine pills, drink as much coffee as I could manage and that I would be placed on a waiting list for one of the 18 beds available in the Neurology ward at Queen Elizabeth Hospital, Birmingham where I was to

have a blood patch. It later transpired that I never had a spinal leak and trying to lie flat when you have two young children, one only a toddler, at home, a husband who works full time and no family locally to help was just impossible.

I got my bed on December 5th 2014. I spent two weeks in the neurology ward and was seen by more consultants than I can remember – all of whom had a differing opinion. There were only two anaesthetists in the Midlands able to carry out a blood patch so I was waiting for them. All this time the vomiting, tinnitus and pain continued. I was advised not to take painkillers and was not given any due to being told they would make my headache worse. Advice I now completely ignore and take all the pain meds I can get – I will never just accept that level of pain again. I was in a terrible state, became depressed and stopped eating. I had a further seven brain scans, CT scans and hours of testing. I developed a phobia of the MRI tunnel and now have to be sedated to have MRIs.

It took seven brain MRIs to eventually locate a 1.2 cm perforation of the bone in the left sphenoid of the skull which the team of neurologists decided was the most likely cause of the leak. So, cranial and not spinal after all, spontaneous and not due to fracture. At least I had an answer, although I then had the prospect of waiting two weeks over Christmas for an ENT surgeon to see me whilst I sat in hospital. I discharged myself and decided to await seeing the ENT as an outpatient. I made it home just in time to have Christmas day with my children, although I was only up for about an hour of the day.

I saw my excellent ENT consultant in January 2015 where we planned to repair the perforation using pigs intestine (!) to line the skull via endoscopic skull base surgery. The side effects of which could be; loss of sight, facial disfigurement and brain damage. The operation may not even work. Without it, I effectively had an open pathway to the brain and could develop meningitis. The consultant had done it only once before. It was the most unbelievable news – I had a solution but what a decision to make – whether to put myself through this! – with no guarantee of success.

During the wait for my operation scheduled April 21st 2015, I saw many consultants to monitor what they now thought was high intracranial pressure. Each one had a different opinion on whether I should or shouldn't have the operation. No-one really seemed to have an answer.

It was during the wait for my op that I begin to notice very slight improvements in symptoms, so much so, that we kept postponing the surgery until eventually I decided with the ENT consultant and another Neurologist and headache specialist I was now seeing, not to risk going ahead with the surgery. That was exactly four years ago. The first three years I suffered daily symptoms the same as always but on a milder scale, lessening gradually as time went on. Sometimes flaring up every few months for no reason to leave me incapacitated and confused as to why. I lived a careful life at first and then decided that if I had some sense of a life back, I was going to make the most of it and took up pole fitness and running, often exercising with terrible headache, vomiting and fluid dripping from my nose. I'm not advocating such strenuous exercise for any leaker however, for me it gave me a sense of strength and vitality and I'd always been active before, being a "sick" person made me feel worse.

No medical professional had advised not to exercise – the leak was not triggered by physical activity.

Over the past two years, I've been advised to try many different medications to try and alleviate the mild yet ever present feeling of headache and pressure in my head. None of these medications have ever worked. The last year has seen my symptoms continue to gradually improve to the point where I finally feel like I am almost back to normal.

My current consultant, a neurologist and headache specialist has concluded that I suffered a spontaneous Cranial CSF leak from a congenital thinning of the bone in the skull behind my left cheek. The thinning has probably been there from birth but higher intracranial pressure basically blew this hole, allowing the fluid to collect in two subdural hygromas – a CSF leak.

This increase in intracranial pressure may have been caused by sheer exhaustion – due to a preceding two year period of me only getting sleep in 20/30 minute snatches of a total of two hours a night due to our 2nd baby who did not sleep. Or to the head injury.

My ENT consultant said my perforated bone could be like a pepper pot – leaking sometimes and sometimes not. A description that seemed to make sense.

My most recent scan a year ago shows no leak and no hygroma on the brain. The conclusion being that the meninges of the brain can take many years to repair hence why it has taken four years to recover and why I still don't feel quite 100% back to normal but have no active leak. I often need to lie down, not to sleep but to rest. I suffer with fatigue and mild head pressure. I've been advised this could be fluctuating intracranial pressure or that damage to the meninges has caused a bruising type effect leaving me with tendency towards headaches. I think I accept that as the best explanation from all I've heard from the many consultants.

I can live with the mild head pressure and fatigue as I'm back to living a relatively normal, active life now. I have had to make adjustments to my life to enable me to manage symptoms like eating regularly, sleeping well, in order not to get "secondary" headaches.

I am genuinely grateful for every day that I feel well. I know I am not 100% back to normal and wonder if I ever will be. I get frustrated when I have unexplained periods of relapse in symptoms and am frightened of the leak returning. My consultant has told me to let it go and not live in fear but I now know the physical pain of a leak and know I am not strong enough to go through it again.

I have sought alternative treatments such as acupuncture and swear that my cranial osteopathy has been the most successful of all the treatments / advice I've ever been given. I know these won't "cure" a leak but for me, with no solution except a risky operation and so many conflicting opinions, it became a matter of managing symptoms.

I have tentatively returned to work in the last year and built up my hours slowly and last year I retrained as a yoga teacher. I now do a job I love,

can physically manage and which has taught me acceptance and gratitude.

I'd like my experience to give other leakers hope that I am proof there can possibly be improvement and resolution without invasive procedures and that in the midst of feeling hopeless, there may just be better times ahead.

I also hope my story clarifies some points for other leakers which I feel are frequently misunderstood;

1. You don't necessarily have to have an upright headache (ie low pressure) to have a leak. I DID NOT ever have an orthostatic or upright headache that disappeared when lying down. It is not a definitive symptom.
2. People with cranial leaks don't always leak huge amounts of fluid out of their nose, ears and throat. I had two leaks of fluid into my throat which I believe triggered the healing process – (as if the pressure had finally been adjusted). I do leak out of my nose, in very small amounts, doctors had tried to test the fluid but timing was never right, so who knows if it is CSF fluid? No consultant I've seen was ever very interested in physical leaks from nose, throat or ears – saying it happens to some and not to others. They set very little store by it. It's not the definitive symptom of a leak.
3. A blood patch WILL NOT solve a cranial leak!
4. Bone can regenerate – just like any other fracture or break – there is the possibility my perforated bone has sealed. Who knows!



I'm Jenny Pople and I'm a Research Scientist at Unilever R&D near Bedford, UK. I had my first CSF leak in 2012 and I'm currently managing my third leak which hasn't responded well to blood patching. I'm a functional leaker so manage reasonably well in the mornings but struggle significantly with symptoms later in the day. My role is mainly office-based with a short commute time but to manage my symptoms I work at home in the late afternoons where I can lay flat and use a laptop stand. My employer agreed in 2017 I had a long-term disability and we would work together to make reasonable adjustments to the office to accommodate me.

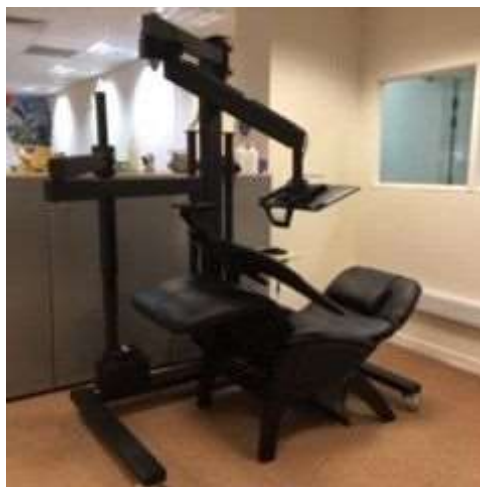
To fund the adjustments, I applied for a DWP access to work grant. This is open to anyone with a disability in work or seeking work and you don't need to be in

receipt of any disability linked benefits to apply. The application process was straightforward. An accessor then came to my place of work to discuss my condition and what physical adjustments could work. I really needed some equipment to enable me to work laying flat for at least part of the day. The DWP initially offered some basic equipment which my employer did not feel was appropriate or adequate. Our occupational health department identified another more suitable option and appealed to the DWP to fund this, which was successful.

They identified the zero-gravity workstation and recliner chair supplied in the UK by a company called back2. The workstation has a multi-adjustable monitor holder, an adjustable tray for keyboard/mouse and a small side table to hold a laptop & drink. <https://www.back2.co.uk/zero-gravity-workstation.html>. The keyboard tray is on hydraulics and lifts up and down using touch button. We have teamed this with the zero gravity recliner chair <https://www.back2.co.uk/back saver-mb-2020-zero-gravity-recliner-chair.html>. This is a leather office chair which adjusts back a long way but not quite completely horizontal. I tested the chair in their London showroom before purchase, but the workstation is not on show. The workstation can be used with a flat bed or couch if needed. I had to be very patient as the workstation was shipped from the USA and took four months to arrive and we had to sort out a monitor, handle and some very long cables. My employer is very safety conscious, so we are currently doing a risk assessment and making sure it's as easy and safe as possible for me to use. I'm already the envy of the office and should be using the workstation in the next week or so. I'm hoping to lay flat for part of the day and upright at my normal desk / in meetings the rest of the time as this combination is how I seem to manage my symptoms best.

If anyone has any questions, would like to see more photos or would like to see the workstation in person please drop me an email and I'd be happy to help. jennypople@btinternet.com.

Thank you, Jenny for writing this article for the newsletter and for sharing such helpful information.





BASH 8th Biennial National Meeting on Headache

17 - 18 January 2019 - Hull

By Clare Sargeant

It was early in the morning on a cold day back in January that Clare Joy and I set off for Hull to attend the 8th Biennial BASH National Meeting on Headache. The event ran over two days and global experts covered a wide range of topics on headache diagnosis, management and research. It is the largest headache meeting in the UK and was widely attended by delegates from all over the UK and abroad. In attendance were general Neurologists, Neurology Trainees, General Physicians and General Practitioners.

We were the first to arrive at the venue and we couldn't believe our luck to see

sofas lining the edges of the large hall. It wasn't long before the 300 delegates had filled the room and we were busy engaging with clinicians and handing out our leaflets.

The first talk of the conference was about the history of migraine. It was fascinating to hear that migraine has always been with us; the ancient Greeks wrote so vividly about migraines that any migraineur would relate to what was written thousands of years ago.

Clare and I needed to have regular breaks lying on the sofas conveniently placed at the back of the hall, unfortunately it was not easy to hear the speakers while flat at the back but we did learn :

- Botox is a well tolerated effective treatment for many patients with chronic migraine.
- Migraine can be induced by giving willing volunteers nitroglycerin making it possible to scan and do blood tests during a migraine episode. By these methods much has been discovered, which has led to effective treatments.
- Regulating our internal body clock can reduce vulnerability to migraine.

During the coffee and lunch breaks we had a steady stream of visitors to our table and we were encouraged by the number of delegates keen to find out more about the CSF Leak Association. Our leaflets, posters and fact sheets were very popular and disappeared fast.

Dr Matharu, Head of our Medical Advisory Committee (MAC) gave an informative talk on cluster headaches and the treatments available.

Of special interest to us was the presentation on Spontaneous Intracranial Hypotension (SIH) by a member of our MAC, Dr Brendan Davies. A subject he said that was dear to his heart; he recommended the CSF Leak Association website as an excellent source of information and he suggested the delegates visit our stand after his talk. He went on to explain:

- SIH was first described in 1938, it is increasingly being recognised and he believes it much more common than the published figure of 5 in 100,000.
- Research into SIH is increasing with only one research paper published in 1991, now there are 40-50 papers published every year.
- Headache is not always the most prominent feature, otological symptoms can be most troublesome including muffled hearing, sometimes deafness, photo / phonophobia, neck stiffness and tremor.

On encountering a patient with an orthostatic headache he urged the delegates to think :

- Could this be SIH?
- What tests and scans can be done to support a diagnosis?
- Where is the leak?
- Why is there a CSF leak? Could there be a connective tissue condition like Ehlers Danlos Syndrome?

His main message to the delegates was how to spot SIH on MRI images stating the key signs to look out for can be remembered by the letters SEEPS.

S Sub dural fluid collections

- E Enhancements - nonnodular diffuse pachymengial enhancements
- E (Venous) Engorgement and swelling
- P Pituitary hyperemia
- S Sagging of brain that can look like chiari

He went on to say if conservative care fails the treatment of choice is an epidural blood patch (EBP) which can be a curative procedure without knowing where the leak site is. One study showed that with an EBP given within 45 days of symptoms starting, 90% of patients got immediate relief with a long term cure rate of 60%. A second EBP given soon after increases the cure rate to 70- 80% even when the MRI was normal. After 2 EBPs efficacy reduces.

He stated some possible reasons for an EBP not being effective are - dural tears, bony microspurs, menengial diverticuli and CSF venous fistula.

He emphasised that a CSF leak can happen spontaneously and they may not be fixed with only one EBP, some people needed several EBPs before the leak is sealed. After two unsuccessful EBPs he recommended referral to a specialist centre where a targeted patch under x-ray guidance could be performed.

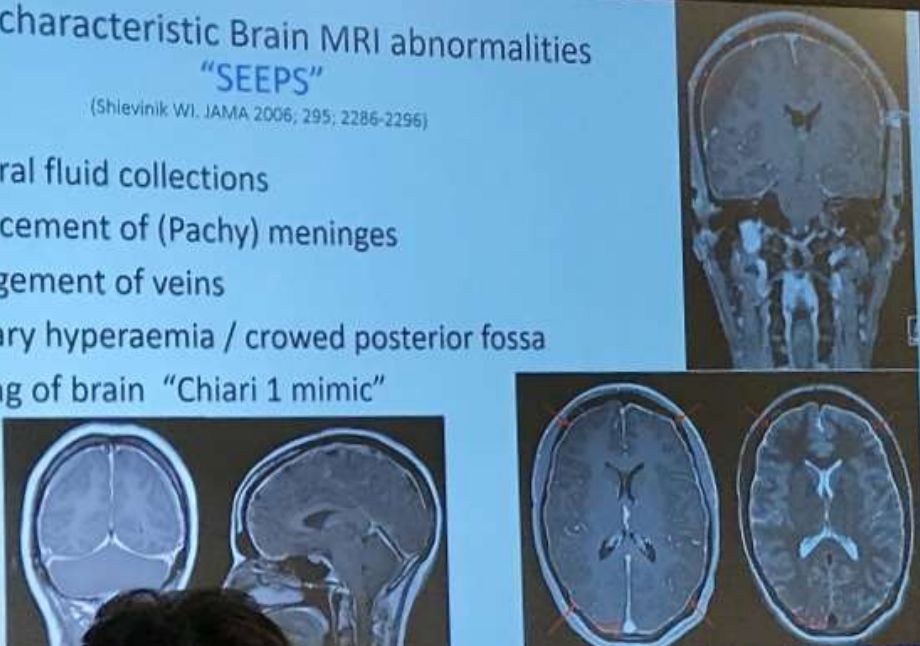
After the coffee break Dr Sarmad Al-Araji gave an interesting presentation on "CSF venous fistula – a rare cause of spontaneous intracranial hypotension".

We had a rewarding two days learning about many aspects of headaches and it was good to meet up with our friends on the headache circuit and exchange ideas with each other. We are very grateful to Dr Ahmed for inviting us to attend and providing us with the opportunity to raise awareness of CSF leaks amongst clinicians who will spread the word more widely about how to recognise and treat CSF leaks.

If anyone is interested in helping out at future events please contact volunteer@csfleak.info It will be great to meet you!

The 5 characteristic Brain MRI abnormalities "SEEPS"
(Shlevinik WI. JAMA 2006; 295; 2286-2296)

- S** Subdural fluid collections
- E** Enhancement of (Pachy) meninges
- E** Engorgement of veins
- P** Pituitary hyperaemia / crowded posterior fossa
- S** Sagging of brain "Chiari 1 mimic"



Upright headache? Think CSF leak!

csf leak

LEAK FACT

Spontaneous CSF leaks are a common cause of upright headaches. They are caused by a tear in the meninges that allows the fluid surrounding the brain and spinal cord to leak out of the head or spine. This can lead to a variety of symptoms, including severe headaches, neck pain, dizziness, and hearing changes. In some cases, CSF leaks can also lead to meningitis or other infections. If you experience any of these symptoms, it is important to see a doctor as soon as possible. A CT scan and/or MRI scan can help to identify the location of the leak. Treatment typically involves a surgical procedure to repair the tear. In some cases, a temporary shunt may be used to divert the CSF away from the leak. Recovery is usually good, but it can take several weeks for the headache to completely resolve.

SYMPTOMS


- Severe, unilateral or bilateral headaches that are worse when upright and better when lying down
- Neck pain and stiffness
- Dizziness and vertigo
- Hearing changes, such as ringing in the ears or muffled hearing
- Changes in voice, such as a hoarse or nasal-sounding voice
- Changes in vision, such as blurring or double vision
- Changes in taste and smell
- Changes in bowel and bladder function
- Changes in skin temperature and color
- Changes in heart rate and blood pressure


DIAGNOSIS


- History and physical examination
- CT scan of the head and spine
- MRI scan of the head and spine
- CSF leak test (beta-2 transferrin)
- Radioisotope cisternography
- Fluorodeoxyglucose (FDG) PET scan

TREATMENT

- Conservative management (rest, hydration, analgesics)
- Medical treatment (steroids, antibiotics)
- Surgical treatment (repair of the tear, shunt placement)



INSTITUTE FOR SCIENCE AND TECHNOLOGY IN MEDICINE



Stop the brain drain



BASHP
 BRITISH ASSOCIATION FOR THE STUDY OF HEADACHE
 registered charity no. 1072789

Spontaneous Intracranial Hypovolemia (hypotension) & CSF Leaks

Dr Brendan Davies
 Consultant Neurologist
 Midlands Regional Headache clinic
 UHNM


NHS
 University Hospitals of North Midlands
 NHS Trust


Cerebrospinal Fluid Leaks





Leaving a gift to charity

As a nation, we're an extremely charitable bunch. In 2017, the British public gave nearly £10 billion to their favourite causes – and a significant chunk of that was donated by people as part of their will, putting paid to that common myth that only the rich and famous leave money to charity when they die. The reality is without the gifts left in wills by people like you and me, many of the charities we know today wouldn't even exist.

When asked, 35% of people in the UK say they'd happily leave a gift in their will once provision had been made for family and friends had been provided. Unfortunately, only 7% actually follow through on this. Legacy income is the largest single source of voluntary income to the charity sector and is vital to the survival of many charities.

After you've taken care of loved ones, you may wish to leave a gift in your will to a charity close to your heart or whose work from whom you may have benefitted. It can be both a way of saying thank you and ensuring that support for others continues into the future.

As well as being of significant value to your chosen charity there are also positive financial benefits to leaving part of your estate to charity. Leaving money to charity can be a way of reducing how much of your estate ends up with the Tax Man. Not only will any portion left to charity not count towards the total taxable value of your estate, but if you leave at least 10 per cent of your net estate to charity then you can cut the rate of inheritance tax you pay.

Legacy gifts that can be left could include a share of your estate after friends and family have been provided for, cash gifts for specific amounts or individual items that can be sold on behalf of the charity. It is also possible to leave 'conditional' gifts that are made only if, for example, all other beneficiaries named in your will die before you.

Leaving a legacy to a charity can be as straightforward as including a simple sentence in your will, but it is recommended you always seek professional advice when making a will. To include a legacy gift in your inheritance provisions you will need the full name, address and registered charity number of your chosen charity ahead of contacting your professional advisor.

If you need any inspiration there are some great stories of unusual legacies out there.

Businessman Richard Colton left 2 rare Ferraris to the RNLI in his will which raised over £8million. He had hoped the sales would raise enough money to fund a new lifeboat to be named after him and his late wife Caroline. Described as "a shy and private man", he was said to be nervous of the sea.

If you are considering leaving a legacy to the CSF Leak Association the information you will need can be found below:

CSF Leak Association - The Cerebrospinal Fluid Leak Charity Registered charity number SC046319
PO Box 5761
STRATHPEFFER
IV15 0AQ

Thank you in advance.



[When to suspect a CSF Leak](#)

This article was brought to our attention by a fellow leaker after it was published in The Australian Doctor Magazine in March 2019.

The article is aimed at GPs and other Primary Care Doctors, to help them recognise symptoms of CSF Leak, and to help raise awareness in the medical community.

Not only has the article been used by patients in their bid for a correct diagnosis, it has also been read by GPs who have then realised that it may relate to some of their patients.

Please click [here](#) to read the article.



Throwback to the Rogues' Gallery, a regular feature in our early newsletters. If you have any CSF Leak Merchandise that you would like to share in action in the newsletter, please send your photographs to polly.walker@csfleak.info

Merchandise can be purchased from our shop - visit by clicking [here](#).



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?

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 Pin this newsletter to your board



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