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Message from our Trustee, Claire Hubbard

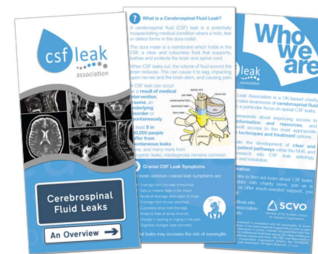
Hello, <<First Name>>.

Welcome to the 5th edition of Leaker Life.

In this edition we are excited to feature the outcomes of our first AGM. Reflecting on our first year and how much has been achieved in such a short space of time was truly remarkable and we hope that you'll join us in celebrating this important milestone in the development of the association.

We have recently produced a fantastic CSF leak infographic – please share as much as possible, download, print, and take to your GP or consultant in order to help us spread awareness.

As always we aim to offer a newsletter that is packed full of interesting news and information about CSF leaks and the association. This time we are launching a competition and also a survey – we love to hear from you and appreciate your feedback and thoughts, so please do be sure to check them out.



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.

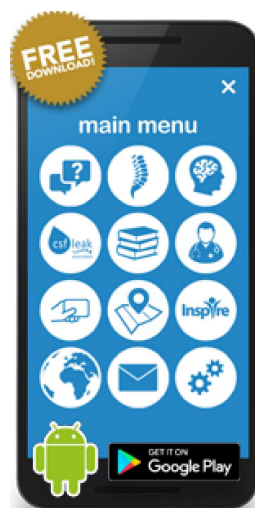
The leaflet is ideal for downloading, printing off and taking with you when you visit your doctor. [Learn more](#)

Last but not least, we wish to extend a very warm welcome to Deborah Lunnon, our newest trustee. Thank you for joining us Deborah, and for all of your hard work that you have already been engaged in on behalf of the association!

Thank you again for reading, and for your ongoing support.

Claire Hubbard

Association Trustee



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

[Find out more](#)



WELCOME...

We'd like to give a very warm welcome to Deborah, our newest Trustee.

Deborah has been a recurrent CSF leaker since 2007, and although she has always been lucky with treatment, in the early days there was absolutely nothing available to support her on her journey; no internet, no information, no support.

In 2014, Deborah had a second CSF leak, followed by a third in 2016. During this most recent episode, her husband came across the CSF Leak Association and it's chairman David Baldwin.

Deborah has noted that the support and information that the Association was able to offer her family was 'amazing and a life line. No more stumbling in the dark'. She felt that she was not actually on her own or an anomaly. Reading the online stories of fellow sufferers and the inability to be diagnosed and treated incensed Deborah and made her determined to change this.

She feels that can only be done by raising the profile of CSF leaks to health care professionals (any and all) and supporting sufferers through their journeys, each of which are completely unique. With this in mind, Deborah feels that she can bring reliability, professionalism, confidentiality, commitment, responsibility and understanding to the role of a trustee for



the CSF Association, and we have no doubt that she will be a huge asset to the team!

Welcome, Deborah!

Upright headache? Think CSF leak!

LEAK FACT
Research shows that at least **5 in 100,000** people each year are affected by spontaneous CSF leaks, with many more suffering from iatrogenic or traumatic CSF leaks. They are not rare, yet are generally under-diagnosed, re-diagnosed as migraines, sinusitis, MPN, tension and other headache disorders to common place, and an average correct diagnosis takes **12 months** from onset.

SPINAL AND CRANIAL CEREbroSPINAL FLUID LEAK

- Clearly pockets of leaked CSF 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.

WOBBLE AND BLENDED VISION

- When you become tilted or double vision may be experienced, often returning after a period of standing.
- For glasses and contact lens wear, pressure or changes may occur.

EYE PAIN AND PHOTOPIHOSIS

- Pain behind eyes
- Pain when closing eyes
- Sensitivity to bright light (photophobia)
- Visual field changes

DRIZZLE AND DROPS

- Cognitive symptoms including memory loss, loss of concentration and inability to maintain train of thought.
- Chronic fatigue, loss of stamina and exhaustion.

NOISES AND TICS

- Tinnitus and clicking often worse when sitting or standing.
- Changes in taste (sometimes metallic or salty)
- Cranial ticks may result in fluid drainage to throat.

HEARDNESS AND BRUINAGE AND HEART RATE

- Ears may particularly when upright or changing position
- Sense of imbalance and dizziness (usually get)
- Flurry, palpitations, palpitations or other myocardial symptoms
- Elevated heart rate and occasionally shortness of breath.

SMELLING AND HEARING CHANGES

- Tinnitus – high pitched, buzzing or/and pulsatile
- Ear pressure, popping or feeling of liquid in ears
- Hearing loss and/or tinnitus
- Sensitivity to sound (hyperacusis).

NECK AND BACK PAIN

- Neck pain, aches and stiffness
- Intercostal pain (between breast/corset blades)
- Generalised back pain (occasionally all nerve roots)
- Flurry, localized pain at the site of the CSF leak.

RELAXING 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 and relieved when lying, but may become less positional over time.

RELAXING PRESSURE AND SENSATIONS

- Pressure behind either eye and
- Pulling sensation from the need to rest.
- Facial numbness, jaw pain and lockjaw
- Crawling or slipping light sensations around top of head.

INTERNAL PRESSURE

- Intracranial hypertension is responsible for many CSF leak symptoms. It normally has a positional (worse when sitting or standing) and other symptoms are similar when upright. Sometimes onset may occur intermittently, but symptoms can build slowly over a number of hours to become a constant dull or throbbing.

EXTERNAL PRESSURE

- Symptoms may be entirely relieved or significantly reduced by lying down after with head lower than feet. The positional element may, however, return over time, and lying down may then provide less relief.

CSF LEAK ASSOCIATION

Find out more about cerebrospinal fluid leaks
www.csfleak.org/uk/yourdoctor

The CSF Leak Association is a Scottish Charitable Incorporated Organisation, Char No. SC2486728
Incorporated in 2011 CSF Leak Association, 18 Park Road

We're thrilled to announce the publication of our brand new CSF leak awareness leaflet/poster, which builds upon the global [#UprightHeadache](https://twitter.com/UprightHeadache) initiative and, we hope, will help to secure swift, correct diagnosis.

This excellent, detailed resource has been produced in consultation with two top UK neurologists and covers many of the key signs and symptoms of a CSF leak.

You can click [here](#) to download a copy in PDF format. It's ideal for printing off at A3 or A4 and we hope that the infographic will be spread far and wide in order to raise awareness of CSF leaks and the symptoms encountered by many leak sufferers.

Please like and share...particularly with your healthcare professionals!



LET'S SEAL & HEAL CSF LEAKS



CSFLEAK.INFO

CSF Leak Association wristbands are a great way to raise awareness of both cerebrospinal fluid leaks and the charity itself.

All of our members receive a free wristband in their welcome pack when they join or renew their subscription, however we're thrilled to now be able to offer additional wristbands for sale on their own.

Shipping is currently free for UK orders; we ship to a range of other countries for a small charge. You can buy wristbands individually or in packs of four. If you're after more than three, packs of four offer better value.



You can purchase wristbands via our website's shop section: www.csfleak.info/shop

#leakweek
Spinal CSF Leak Awareness
Feb 26 - Mar 4, 2017

As you may remember, 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 2017. 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.

In the fourth edition of Leaker Life we featured the first of three live Q & A sessions with the worlds leading CSF leak specialists. In this edition, we summarise the session with Dr Carroll. Once again we wish to express our sincere gratitude to The Spinal CSF Leak Foundation for organising the sessions and for allowing us to feature this summary in our newsletter. In addition, we also wish to express our thanks to Beck Hill for the time and hard work she has dedicated to transcribing the sessions.

**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



DR CARROLL - ANAESTHETIST
Stanford University Hospital



1. IMAGING

There is no one best way, however an MRI of the brain and spine can show signs of fluid outside the dura. Abnormalities can often be seen in the area around a leak rather than the leak itself. We are not sure what percentage of people with leaks show nothing on an MRI scan, and a clear MRI doesn't rule out a leak - although it can confirm a leak. Enough research hasn't been carried out on this.

- CT Myelogram

Can be used to measure CSF pressure but higher readings do not rule out leak. Fluid is tested and protein is often found to be elevated. The patient will be tilted head down for 30-60mins to spread the contrast. Images are much better/

clearer on myelogram than MRI. Better for seeing bone spurs that might cause leak.

- Radionuclide Cisternogram

Some places favour this method of imaging. It can be used to detect skull based leaks - more below on this.

2. INVESTIGATING SOMEONE WITH CHIARI - IS IT SAFE TO DO A LUMBAR PUNCTURE?

- If brain sagging is small then a LP may be carried out. But if the Chiari is severe a myelogram may not be carried out because of the risk of the LP and the neurosurgeon's advice sought. If they are concerned they sometimes go ahead but will patch hole from LP that day to make sure no extra leak/ brain sag.

3. CLEAR FLUID LEAKING FROM NOSE AND EAR?

- Spinal fluid can leak from spine OR skull base. But what's less clear is if a skull based leak whether the patient will suffer with symptoms of intracranial hypotension. It does not seem to - spinal leaks are orthostatic in nature because of the position of the leak. If a leak is from the skull, pressure is not affected as greatly.

- Even when someone seems to have a skull based leak they may well have a spinal leak too. The orthostatic symptoms will be from the spinal leak.

- Dr Carroll patches many people who have fluid coming out of nose and ears and when successfully patched in spine the fluid also stops. So the spinal leak seems to aggravate sinuses or something similar.

- There are 3 tests for skull based leaks

- Ct myelogram up to skull base

- Collect spinal fluid from nose/ ear and test

- Radionuclide Cisternogram - inject radioactive contrast into spinal fluid and scan and do pledget study too up the nose.

4. POST PATCHING PRESSURE CHANGES

- When someone has been leaking for a long time some develop RHP (Rebound Hypertension) when patched. Not sure if this is because they are overproducing spinal fluid or other reasons.

- Papers written suggest this is a benign or temporary problem over days to months.

- Fibrin glue is better at sealing leaks permanently but much more RHP is seen with glue patching.

- Some have RHP for months and months without going away or easing. It's less of a problem with blood than glue. But with blood they often have to keep patching and patching and patching. But on other hand glue means more RHP.

- They use Diamox to treat RHP. Extended release is better. Start 500mg then up to 1000mg twice a day if needed. Lasix is better to add to Diamox but if with Diamox then loose too much potassium . So then need diuretic that doesn't loose potassium to add to Diamox.

5. HOW MANY BLOOD PATCHES DO YOU TRY BEFORE USING GLUE AND HOW LONG DOES IT LAST?

- Fibrin Glue: concentrated blood clotting. So body should clean up like a clot. Not sure if lasts from 2 weeks to 2 months:
- They will often see very small areas of clot on images after 1 month whether with blood or glue.
- Glue is better and more permanent. But more RHP. And glue clots quickly but doesn't spread well so only really use for small targeted patches. 2-3ccs but with blood x8-10 that.
- Always try blood first. If not last try glue.
- Often if imaging is ambiguous the hospital are happier with the use of blood.
- So for those cases they decided try 3 patches then stop if imaging ambiguous - if no progress from patches then stop. So start with blood. Maybe second blood or glue. Then finally try glue. To give patients the best chance with 3 patches. (3 patches might include multiple (up to 3 suspicious sites) patches in different spots at a time.)

6. DEMENTIA AND LEAKS, DEAFNESS AND LEAKS.

- He has not seen deafness resulting from a leak, but has seen hearing affected. Often a reduction in hearing in one or both ears.
- Some people are wrongly diagnosed with Menieres & chronic dizziness.
- If dementia with a story that is suggestive of a leak / could be in line with leak/ connective tissue disorder / Chiari/ POTS then worth looking into. Even with negative MRI.

7. LEAKS AND PREGNANCY.

- Very little written about it.
- Dr Carroll has discussed with wife - Obs Dr.
- He a patient who had leak and got much better but not fully - then got pregnant and leak got much worse.
- They may well be a much higher risk in pregnancy of leaking if have weakness/ chronic leak already - patient will need to think carefully about conceiving.
- If do get pregnant/ decide want a family and some leak issues in past or current you will need better support and pushing to deliver would probably be a problem so might need assisted or C-section.
- If pregnant somewhat limited in scans and fluoroscopy patches etc. But things can be done.
- Pregnant lady needs to talk to OBS Dr and ask them to read up on it.

8. POTS AND LEAKS

- His opinion on this may well differ from other Drs
- EDS is connected to POTS and leaks.
- POTS often connected to connective tissue disorders as well as leaks.
- Leaks often cause tachycardia
- When they found patients with POTS diagnosis. And patched them their dizziness and tachycardia improved or fully went away too.
- Is POTS caused by leaks sometimes or do they have both? etc they have not done enough research but a leak should be considered.

9. VOLUME OF BLOOD TO PATCH.

- More than one location may be patched if anything looks suspicious. Willing to

try 3 areas per patch.

- No more than 45cc total volume split between areas.
- For blind patching the volume may start with 30cc but will increase if patient can tolerate up to 45cc. But no more.
- Some people can pass out if pressure in head gets too high. Not if pressure felt in spine or leg but in head it can be a problem.
- If people have big leaks and very depleted CSF Dr Schievink has been known to try up to 100cc in special cases.
- Stanford never went over or had case they felt needed more than 45cc.

10. HOW LONG DO PEOPLE NEED TO REMAIN FLAT AFTER A BLOOD PATCH?

If patients travel for treatment, it is advisable to wait for 5-6 days post patch before flying. If they're local this is ideal. After being patched they should stay flat at home or in local accommodation for 3 days/ However there is no data on this, but we suggest 3 days to give the patch the best chance of working - procedures take time and energy and carry a risk so we tend to err on the side of caution.

11. ACTIVITY AFTER A PATCH?

For the first six weeks we recommend no stretching, lifting, no gym etc - just normal light activities, but without staying flat for too long because of the risk of DVT.

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



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

Save the Date...



The **Intracranial Hypotension Symposium** to be held on October 14, 2017 will be hosted by **Cedars-Sinai** in partnership with **Spinal CSF Leak Foundation**.

Location:

Casa del Mar, 1910 Ocean Way, Santa Monica, CA 90405

Course Description:

This full-day multidisciplinary Symposium will bring together top clinicians and researchers to share the latest advancements in diagnostics and treatments of this under diagnosed, disabling but treatable secondary headache disorder. This Symposium is expected to elevate awareness in interest in the medical community, stimulate further research and reduce the burden of suffering. Clinicians, researchers and patients are invited to attend. There will be a professional track and a patient/caregiver track.

For more information please click [here](#).





Following the huge success of The Kilt Ride 2016, the event took place again from 26th - 29th May this year, and once again it was not only a sight to behold, but a fantastic opportunity for the association in terms of fund raising and spreading awareness.

There was a great turn out of approximately 70 riders, who were led once again by [The Scotorian Biker](#). The weekend consisted of a full riding tour over two days, this time taking in the north west coast and parts of the NC500, with the initial rendezvous at Cumberland's campsite in Fort Augustus on the south banks of the Loch Ness.

The bikers spent both Friday and Sunday night here, with Saturday night spent on the west coast at Achiltibuie. We are thrilled to announce that the event has raised over £1600 thus far this year for the CSF leak Association!

Thank you to Ray and the many bikers that joined him on the tour!





If you haven't already – why not join up?

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.



Name: Donia Lindo

Type of Leak: Spinal

Hometown: Portsmouth

Current Leak Status: Read on to find out...

My name is Donia Lindo and I am 30 years old.

My CSF Leak journey started April 2016, when I was 17 weeks pregnant. The first 15 weeks of my pregnancy were plagued with morning sickness and when I hit the 15 week mark I finally got some rest bite and thought that was it. Then the headaches started. Starting with a pulsing sensation in my head when moving and progressing into excruciating head pain and having to be horizontal within a week. From then on, my journey was a living nightmare. I made multiple visits to the doctor, ED and out of hours services, only to be told that it was a pregnancy related migraine and the strongest pain relief I would get is paracetamol. Eventually I was admitted to hospital after spending 4 weeks in bed. This was when I met my neurologist (my saviour!). She recognised the symptoms and suspected a CSF leak! She requested an MRI scan of my brain and a lumbar puncture. She advised me that she would be on holiday the next week but upon her return she said she would come back and see me and discuss the results.

The week she was on holiday was the week I had the MRI and my lumbar puncture.

By this point I had been horizontal for 5 weeks, unable to move my head, photophobic, suffering from phonophobia and clearly 'dry!' Following my Lumbar Puncture my rhomboid spasmed and unfortunately left me even more debilitated than when I had entered the hospital. To my horror the next day I was also told to go home, take pain killers and drink plenty of fluids! I was not allowed diazepam for my muscle spasm in

my back because I was pregnant so I literally could not move my head or arm. I did not sleep the whole night as the pain was unbearable.

A junior doctor came to see me and apologised and said I didn't have to go home, but I was completely reliant on other people to do the simplest of tasks. My mother stayed the night to help me as the wait for the call button was around 20 minutes. The next morning the ward nurse marched into my room (I had my own room as it was the only place they could switch off the lights). She forced me to stand up, tears were streaming down my face due to the pain, and she said "of course you will feel dizzy, you have been laying down for weeks". It was then I realised that they don't understand what's wrong with me. It was then I made the decision to discharge myself, against my family's wishes. My twin sister got me a wheelchair and a sick bowl, I wore my blindfold and she wheeled me out. I was in agony. Being sick all the way home. I finally got in my bed and my fiancé gave me round the clock care. From back massages, bed washes, feeding me, helping me crawl to the toilet. It was awful, but I felt so much more secure in my own home with people who knew and understood what was wrong with me.

My neurologist returned from holiday and was horrified that I had been sent home! She rang to apologise and told me to return to hospital as soon as I could as she wanted me to have a blood patch. I returned the following day excited that I would finally get some relief. I was so worried. By this stage I was a bag of bones as I had lost so much weight from morning sickness and being unable to eat. Heartburn is bad enough being pregnant but mix that with trying to eat all your meals lying down and it resulted in me having complete loss of appetite. I was so worried about my baby's health! My MRI was all clear and I was diagnosed with an idiopathic CSF leak. I got instant relief from the blood patch! I was elated! On top of the world! I was also naive and didn't receive any advice regarding after care. I returned to work 2 weeks later, picked up a terrible cold with a hacking cough and 6 weeks later I was leaking again. My neurologist gave me her telephone number, so I called her and she got me in for another blood patch and again, I had instant relief.

It was decided that I would have further tests once I had given birth to try and find the cause of my leak.

The rest of my pregnancy went without incident, CSF incident that is. I did end up in hospital with a chest infection and ended up on crutches with SPD. I regained weight and went about my normal life as best as I could while being pregnant. I had meetings with obs consultants and anaesthetists who all decided they were happy for me to go ahead with a normal delivery. Their theory was that some women get CSF leaks from epidurals or spinal blocks and they would normally agree it was safe for natural delivery for their next birth.

I travelled to Scotland to have my baby. My labour lasted 2 and a half days. I had an epidural the later part of day 2. This had to be fiddled with as it didn't work properly. Due to me failing to progress I had an emergency C-section. They decided to give me a spinal block as they were not happy with the epidural. My daughter was born healthy and I was discharged from hospital 2 days later.

12 days after giving birth I leaked again! I was still in Scotland. I went to the local hospital and the doctors contacted my neurologist and she agreed for me to have another blood patch. Instant results again! The doctors were not convinced that the epidural/C-section was the cause of my leak as they said, I should have shown symptoms 3 days later not 12.

I had an out-patient -appointment for an MRI of head, neck and spine and the results

were all clear.

5 months went by and wait for it...I leaked again! This time I think the cause was doing exercise. Rather than taking it easy (because I didn't know), I went back to how I used to train. 5 days a week. A variation of swimming, circuits, running and cycling. This time I had a MRI of my brain with contrast another blood patch, instant results!

A month later I was leaking again!! This I think was because my house had been subject to a flood and I had to move. (Stress overload and having no family around meant I probably had to lift things I shouldn't have). This time I was given a CT Myelogram (which was clear) and an LP (opening pressure 16). It was around this time that I decided to start Vlogging. I felt that family and friends did not understand my condition and I didn't really understand it either, so wanted to reach out. You can check out my Vlog at the link below and follow my story further there.

A month later, I slipped on a wet floor and I leaked again!!! My neurologist again arranged a blood patch. This is blood patch #6 if you have lost count! again instant relief.... and my fingers are tightly crossed that this is 'the one'!

Thank you for taking time to read my story! Sorry if I lost some of you along the way. Since I have been Vlogging, my eyes have been opened more to the extent of this horrible, debilitating condition. I feel I am lucky that I have such an understanding neurologist and employer. It makes me sad that other people are not being treated the same! I want people to know that it has been a very steep learning curve for me. The main thing I wish I knew was how to look after myself after a blood patch as I was never given any information -my knowledge has come from looking at this fantastic website and being part of support groups. I feel that my Vlogs have helped me with not only my journey, but others too! I have had lots of private messages and I am happy to share my experience if it can help somebody else.

Donia's Vlogs are fantastic - a really creative and engaging way to both share her story, and also spread awareness of CSF leaks. Please be sure to check them out! Thank you Donia for sharing your story.





We're on the hunt for photos of your CSF leak Association merchandise in action...

The most interesting photograph will win a limited edition CSF leak / Kilt Ride 2017 t-shirt!

Send your photos to us at newsletter@csfleak.info by midnight on 31st August 2017

We will announce the winning photograph in the Autumn newsletter! Good luck and happy snapping!



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



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!

**THE ANNUAL
GENERAL
MEETING**



Annual General Meeting

CSF Leak Association AGM 2017

We held our inaugural AGM on the 2 May 2017. It was good a good opportunity to look back over the past 14 months and see how much we have achieved. Despite all, bar one, of our Trustees having a CSF Leak themselves, we've done a lot. Our Annual Report sets out in detail our achievements with highlights including:

- Publication of a new overview leaflet, with input from two top UK neurologists;
- Reviewing and updating of existing factsheets, with work commenced to add new factsheets to the series;
- Creation of an online database of CSF leak journal articles, with direct links to PubMed/PMC etc.;
- Partnership working with other organisations, including the Spinal CSF Leak Foundation in the USA;
- Groundwork for the establishment of a Medical Advisory Committee;
- Reviewing and updating of an online searchable database of UK/EU doctors with experience of CSF leaks;
- Publication of an Android App for use on mobile devices, including phones and tablets;
- Commencing outreach work with other bodies, such as the Orphanet, EDS and brain/spine charities, Inspire CSF Leak support forum;
- Establishment of a quarterly Association newsletter, called 'Leaker Life';
- Undertaking over 670 volunteer hours;
- Support for a number of awareness and fundraising events, including the Kilt Ride 2016, Tough Mudder North West, a number of sponsored runs/walks and other events; and
- Opening for membership.

Our Financial report detailed our healthy and steady income. This has been in no small part thanks to some generous individual donations, donations from organisations and trusts, and a number of fantastic fundraisers. In total we received £7810 and spent £1256. It was agreed to re-appoint our existing independent examiner who kindly offers their services of verifying our accounts for free. Over the coming 6 months we will be developing our business plan which will enable us to plan ahead financially and set out a strategy for achieving our goals.

6 of our existing Trustees were re-elected and we welcomed on board our new

Trustee Deborah Lunnon. We will be putting her graphic design skills and great sense of humour to good use. We also thanked 2016/17 trustee Pete Marnick, who did not seek re-election as a Trustee but has contributed significantly to the work of the charity over the past year.

Members will be pleased to note that it was agreed that Membership fees should remain the same for the coming year. We also agreed changes to the Constitution regarding the number of Trustees required to make Board Meetings quorate and how proxy votes can be used. This will enable us to progress our work more efficiently and expediently at Board meetings and enable all proxy votes submitted for member's meeting to be utilised.

Full details of the AGM can be found in the AGM minutes along with the Annual Report. These are available within the member's section of our website.



Rachael Ebeling

Recently completed the Brighton Marathon in order to raise funds for the CSF leak Association!

I am a wife, mother of two and a full time primary school teacher. I was living a normal healthy life until my world came crashing down. After a nasty chesty cough I began to feel worse than I had ever felt in my life. Following months of GP appointments, consultant visits, MRI scans I was finally under Neurology in Queens Square London with a suspected spontaneous CSF leak. After a long awaited ICP bolt procedure it was confirmed I have low pressure. Over the last three years I've tried everything suggested to try and fix the leak and I'm currently waiting for my third epidural blood patch. I've had some bad relapses but since the second blood patch in March 2016 I found my quality of life became a little easier. This inspired me to work towards something amazing while I was physically able and raise money for the CSF leak association at the same time.

I picked out the biggest of challenges for a CSF leaker to complete: The Brighton Marathon. I knew my determination would get me through the 26.2 miles but I was less confident that my upright body wouldn't let me down. I decided to walk and run where possible with no finishing time in mind. I just aimed to complete the Marathon safely with my sister by my side.

My training plan didn't get off to a good start. I found that working full time I needed to

rest and lie down in the evenings and weekends. I also had to consider making sure my two young children's needs were met first and foremost. As time moved along and my head was feeling manageable again, I began training with my sister. We built up the length of the walks and runs until we managed 12 miles, 16 miles and 18 miles ahead of the Marathon. On each run my head felt comfortable but following each big run my head would feel unbearable for a day or two. Overall though I did notice my head improving a little. Exercise raises blood pressure and I have very low blood pressure so it seemed to work in my favour. I felt hopeful as the previous year I was in such a bad way I could barely get through a morning let alone a Marathon!

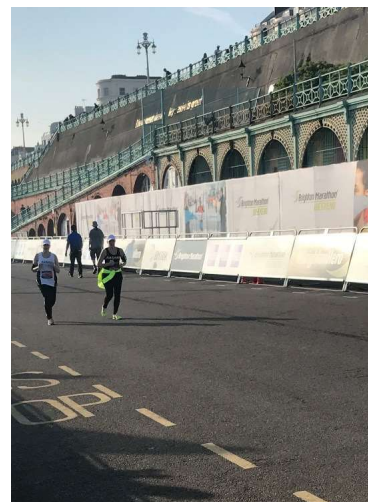
The day of the Marathon arrived and so did the sun. It was the hottest day of the year so far! It made me nervous as the heat really affects my head. We set off at the start line and the atmosphere was electric! I felt incredibly proud that I was actually giving it my all and running through my home-town with all the cheering crowds. For years I've watched friends, family and inspiring people run the Brighton Marathon but there I was in the thick of it.

The first mile was tough starting up a hill in the heat and regulating my breathing. The next few miles were amazing and I was buzzing. I managed to run half of the Marathon but then things got tough! My head began to throb from the heat and despite drinking lots my body needed more hydrating. A foot injury appeared again so we made the decision to walk the last 12 miles. Mile 18 onwards is where my body and mind battled against each other. I nearly gave up but my sister who I was running with, family, friends and the children I teach cheering me on gave me all the encouragement I needed to keep going.

We walked towards the final stretch and the remaining crowd spurred us on to run the last bit. We pushed through the pain together and made it through the finish line. It might have taken us almost 8 hours but we did it! Although it was one of the toughest experiences of my life it was worth every mile to know that on this day my CSF leak couldn't hold me back.

I would like to thank everyone who donated towards the CSF Leak Association and supported the charity that supports people like me.

A huge thank you Rachael for completing such a difficult challenge on behalf of the association!



If you'd like to plan a fundraiser and would like our help, please do get in touch! We'd love to feature your story in the newsletter:

newsletter@csfleak.info



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

NHS Choices Website

We're delighted to have made some headway recently in order for CSF leaks to feature more explicitly within the NHS Choices website. The Association now features as an external link within both the Ehlers-Danlos Syndromes and Marfan Syndrome pages:

NHS choices Your health, your choices

Enter a search term

Health A-Z | Live Well | Care and support | Health news | Services near you

Ehlers-Danlos syndromes

Share: [Icons] Save: [Icons] Print: [Icon]

Overview | **Clinical trials** | Community


Ehlers-Danlos syndromes

Ehlers-Danlos syndromes (EDS) are a group of rare inherited conditions that affect connective tissue.

Connective tissues provide support in skin, tendons, ligaments, blood vessels, internal organs and bones.

There are several types of EDS that may share some symptoms, including:

- an increased range of joint movement ([joint hypermobility](#))
- stretchy skin
- fragile skin that breaks or bruises easily



The different types of EDS are caused by faults in certain genes that make connective tissue weaker. Depending on the type of EDS, the faulty gene may have been inherited from one parent, or both parents.

Sometimes the faulty gene isn't inherited, but occurs in the person for the first time.

Useful links

NHS Choices links

- Joint hypermobility
- Joint pain
- Living with pain

External links

- Ehlers-Danlos Support UK
- Hypermobility Association
- Leaker's Challenge
- CSF Leak Association

Physiotherapy

Find out how physiotherapy can help promote healing and wellbeing



Leaker's A-Z : E through G

Elliotts B

Elliotts B is a sterile, non-pyrogenic, isotonic solution containing no bacteriostatic preservatives. Elliotts B solution is often used as a diluent for intrathecal administration of methotrexate sodium and cytarabine. It is also used alongside intrathecal contrast in order to raise intracranial pressure and maximise the chances of the location a CSF leak being

Epidural blood patches are rarely successful for cranial leaks. Patches used to treat anterior spinal leaks or spinal leaks in the cervical region may be less effective.

Epidural Space

The epidural space is an anatomic space that is the outermost part of the spinal canal. It is the space within the canal (formed by the

disclosed by CT and MRI imaging.

Epidural

The term 'epidural' is a simplified and all-inclusive term used to refer to techniques such as epidural analgesia, epidural anaesthesia and epidural blood patch. These techniques involve a needle or catheter being placed into the anatomic space between the outermost part of the spinal canal and the dura. Epidural techniques frequently involve injection of blood or medication into the epidural space.

Epidural Blood Patch

An epidural blood patch is a surgical procedure that uses autologous blood in order to close one or more holes in the dura, usually as a result of a previous lumbar puncture or epidural anaesthesia, although hole may also occur follow trauma or spontaneously. It is the most common treatment for a CSF leak that does not respond to conservative treatment, such as bed rest.

Low-Volume Patch

In a low-volume blood patch, where the site of a cerebrospinal leak is known, an epidural needle is inserted into the epidural space at the leak site and a small amount of the patient's own blood is injected (approximately 4-5ml) in order to 'patch' the meninges. The procedure carries the typical risks of any epidural puncture. However, even though it is often effective, further intervention is sometimes necessary.

High-Volume Patch

In a high-volume blood patch, where the precise location of a cerebrospinal fluid leak is not known, an epidural needle is inserted into the epidural space around L3/L4 in the lumbar region. A relatively large amount of the patient's own blood is

surrounding vertebrae) lying outwith the dura mater (which encloses the arachnoid mater, subarachnoid space, the cerebrospinal fluid and the spinal cord). The epidural space contains lymphatics, spinal nerve roots, loose fatty tissue, small arteries and a network of large, thin-walled blood vessels called the epidural venous plexus.

Extra-Dural Fluid Collection

See 'Pseudomeningocele'.

Fibrin Glue

Fibrin glue (also called fibrin sealant) is a formulation used to create a fibrin clot. It is made up of fibrinogen (lyophilised pooled human concentrate) and thrombin (bovine, which is reconstituted with calcium chloride) and is applied to tissue sites to glue them together. It is commonly used to seal CSF leaks where blood patches have failed, or in combination with autologous blood. It is also used during neurosurgery.

Fluoroscopy

Fluoroscopy is an imaging technique that uses x-rays to obtain real-time moving images of the internal structures of a patient through the use of a fluoroscope. In its simplest form, a fluoroscope consists of an x-ray source and fluorescent screen between which a patient is placed. However, modern fluoroscopes couple the screen to an x-ray image intensifier and video camera allowing the images to be recorded and played on a monitor.

The use of x-rays, a form of ionizing radiation, requires the potential risks from a procedure to be carefully balanced with the benefits of the procedure to the patient. While physicians always try to use low dose rates during fluoroscopic procedures, the length of a typical procedure often results in a relatively

injected (approximately 20ml). The high volume means that the blood can travel around the epidural space in order to 'patch' the meninges.

It is thought that this procedure can be successful up to 8 vertebrae from the injection site. The procedure carries the typical risks of any epidural puncture, however due to the additional volume of blood injected, the risks tends to be higher than a low volume patch. Success rates are thought to be in the region of 40%, however even where it is effective, further intervention is sometimes necessary.

One school of thought is that blood patches work by way of the clotting factors of the blood, which close the hole in the dura. Another is that the blood, acting as an irritant, encourages the body to scar and heal. It is also postulated that symptom relief immediately after an epidural blood patch may be due to more of a compression effect than sealing the leak itself.

high absorbed dose to the patient. Recent advances have reduced the radiation dose to the patient.

Gadolinium

Gadolinium is a chemical element with symbol Gd and atomic number 64. It is commonly used as a contrast alongside MRI imaging. Once injected into the blood stream or CSF, gadolinium-based contrast agents accumulate in abnormal tissues of the brain and body. This accumulation provides a greater contrast between normal and abnormal tissues, allowing doctors to better locate uncommon tissue formations or, when administered intrathecally, CSF outwith the thecal sack.

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



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.inspire.com/groups/spinal-csf-leak

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