



Message from the Trustees

Hello, <<First Name>>.

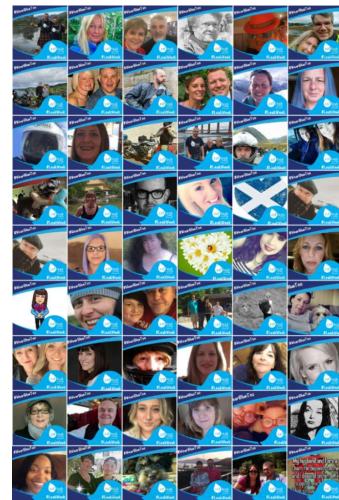
Welcome to the Spring 2018 edition of Leaker Life.

In this edition we welcome our new Trustee, Tamsin Trevarthen, who we are really excited to be working with.

We take a look back over Leak Week 2018 and its highlights, and we also feature a survey to gather your feedback on the awareness week - it is only six questions long, so it will take only moments to complete, but your responses will be a great help to us in planning future events.

Rob Edwards jumps into the Leaker Spotlight where he has kindly shared his story; and we have also included a couple of pleas - for membership renewals, volunteers and focus group members. We'd love to have you involved, so read on!

As always, the newsletter features lots of other interesting CSF leak related items, so without further ado, thank you again for your support and we hope you enjoy this edition!



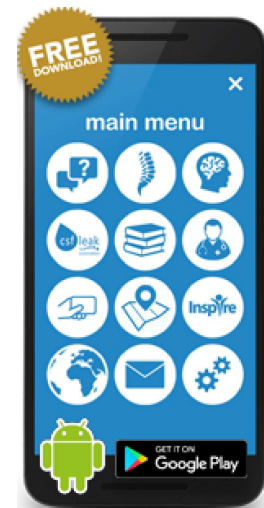
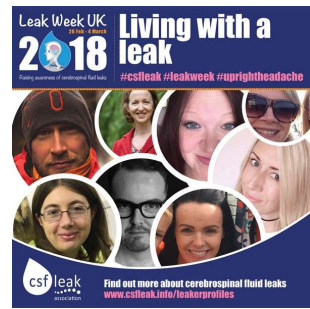
Leak Week 2018

What an action packed week it was! Take a look back over the awareness week and give your feedback - please complete a short survey so that we know how we did, if we missed anything, and what you'd like to see next year!

With best wishes

David, Polly, Debs, Deborah, Tamsin and Clare

The Team of Trustees at the CSF Leak Association



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

[Find out more](#)



NEWS



Latest news from the Board of Trustees



We're delighted to introduce our newest Trustee, Tamsin Trevarthen, who joined the Board earlier this month.

Tamsin developed a spontaneous spinal CSF Leak in January 2011, six months after landing her dream job which had involved relocating to Ireland. Awareness of CSF leaks in Ireland was extremely limited which meant that the path to diagnosis was fraught with difficulty, resulting in both diagnosis and treatment in the UK. After multiple blood patches and a VP shunt Tamsin's leak is now managed although she has developed chronic migraine along the way. Tamsin's professional background is in Human Resources and she hopes to apply that knowledge combined with her enthusiasm for providing other leakers with the support that she missed in her journey, in supporting the Association in their future endeavours.

Welcome aboard, Tamsin!



The 20th January saw the inaugural CSF Leak Association Medical Advisory Committee meeting at the National Hospital for Neurology and Neurosurgery in London.

A group of doctors from around the UK, along with members of our Board of Trustees and our Patient Representative, met to discuss cerebrospinal fluid (CSF) leaks and to begin to work together to raise awareness and secure progress within the UK health systems.

The meeting was a culmination of almost two years of work by the CSF Leak Association and was the first time that medical professionals met around a table with the sole intention of talking about health care as it relates to this debilitating and under-diagnosed condition.

In attendance were:

- Dr Manjit Matharu, Consultant Neurologist, NHNN, UCLH NFT
- Mr James Walken, Consultant Neurosurgeon, Aberdeen Royal Infirmary, NHS Grampian
- Dr Anthony Ordman, Consultant in Pain Medicine, Royal Free Hospital, Royal Free London NFT
- Dr Changez Jadun, Consultant Neuroradiologist, Royal Stoke University Hospital, UHNM NT
- Dr Simon Ellis, Consultant Neurologist, Royal Stoke University Hospital, UHNM NT
- Polly Walker, Trustee, CSF Leak Association
- Deborah Lunnon, Trustee, CSF Leak Association
- Clare Joy, Trustee CSF Leak, Association
- Cerian Baldwin, Trustee, CSF Leak Association
- Sarah Mead, Patient Representative

With apologies received from:

- David Baldwin, Chair of the CSF Leak Association
- Dr David Butteriss, Consultant Neuroradiologist, The Newcastle-upon-Tyne Hospitals NFT, Royal Victoria Infirmary
- Dr Brendan Davies, Consultant Neurologist, Royal Stoke University Hospital, UHNM NT

An overview of the CSF Leak Association's work to date and plans for the future were shared, followed by an acceptance of the MAC Terms of Reference. Dr Manjit Matharu was elected as chair and Clare Joy was elected as Secretary.

Sarah Mead was also in attendance in her capacity as current patient representative. The remit of the patient representative is to represent the CSF Leak Association's membership, and patients more generally, within the organisation and, in particular, on the Medical Advisory Committee.

Throughout the afternoon, encouraging and in-depth discussions took place focusing on:

- a review of current literature and website information;
- gap analysis of current content including specific requests for guidance resulting from patient survey;
- the NHS Information Standard and the Association's road to accreditation;
- a proposed conference/symposium and patient day in the UK;
- securing the addition of CSF leak information on the NHS Choices and NHS Inform websites;
- guidance on creation of an approved NHS pathway for CSF leaks; and

- an agreement of annual objectives.

Whilst realistic about the scale of the task ahead, all parties were deeply encouraged, enthusiastic and positive about the future, secure in the knowledge that a firm working relationship has now been established between the Association and the MAC. This was a historic meeting for CSF leaks in the UK.



(From front to back) Polly Walker, Clare Joy, Dr Anthony Ordman, Deborah Lunnon, Mr James Walken, Sarah Mead, Dr Manjit Matharu, Cerian Baldwin, Dr Simon Ellis, Dr Changez Jadun.



Our first UK based awareness week ran from the 26th February – 4th March 2018, and what a week it was!

The core theme for the week was ‘Life with a CSF leak’, with each day focusing on a different aspect of living with a CSF leak. If you missed anything, want to catch up, or just revisit our animation, the facts, materials, and real leaker life videos and stories, you can do so by clicking on the links below.

Monday / [What is a leak?](#)

Tuesday / [Symptoms](#)

Wednesday / [Diagnosis \(plus Rare Disease Day\)](#)

Thursday / [Treatment](#)

Friday / [Aftercare](#)

Saturday / [Life with a CSF leak](#)

Sunday / [About the CSF leak Association](#)

Some of our highlights of Leak Week:

We were over the moon to see the Kilt Riders photographed alongside the world famous Kelpies, illuminated blue for the evening of 26th February to kick the week off and raise awareness of CSF leaks.



We asked you to #wearbluetoo to raise awareness, and boy, did you rise to the challenge! We saw blue hair, nails, glasses, not to mention a whole array of

blue garments, and brilliantly crafted outfits. We can't let the opportunity pass without thanking each and every one of you for participating, for showing great humour, spirit, and creativity, even when suffering. An extra special mention must be made to John Jackson, posing fresh out of surgery; Leaky Leah for her ingenious and hilarious creations, and of course, our very own Chairman, David Baldwin, for braving the Beast of the East for a chilly #wearbluetoo shot!



The Leaker stories – shared by video and text from a number of leakers – did an outstanding job of raising awareness of CSF leaks, whilst hopefully assuring other leakers that they are not alone in their battles, and that hope is well and truly out there. You can read and watch our patient stories by visiting our website or by clicking [here](#).

SPINAL LEAKER STORY

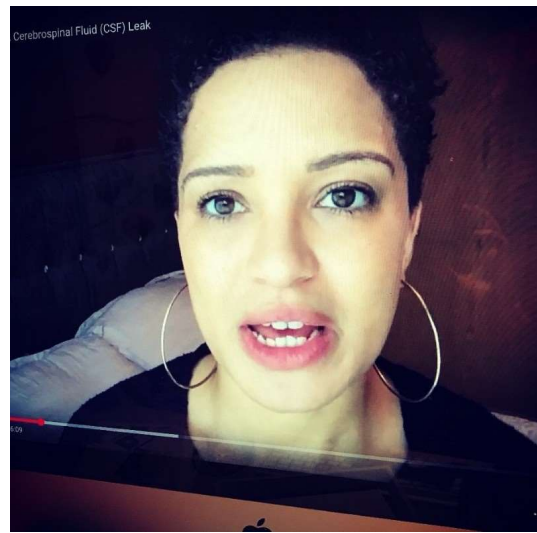


csf leak
association

"I spontaneously developed even more symptoms, including 'end of days' head pain..."

Read my story at:
www.csfleak.info/profiles/robinpalmerhosking

Do something good for charity and support the CSF Leak Association today:
www.csfleak.info/donate



CRANIAL LEAKER STORY



csf leak
association

"As the weeks went by I couldn't look after my son..."

Read my story at:
www.csfleak.info/profiles/sarahhollands

Do something good for charity and support the CSF Leak Association today:
www.csfleak.info/donate

The CSF leak facts attracted a great deal of attention far and wide. You can download your own copy to print and share by clicking [here](#).

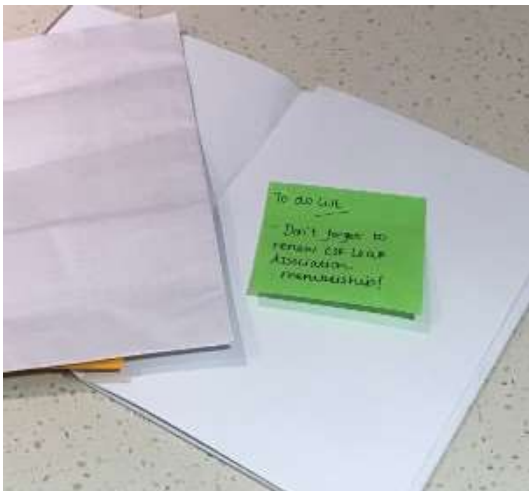
<p>LEAK FACT #1</p> <p>RESEARCH SHOWS THAT AT LEAST 5 in 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #2</p> <p>ON AVERAGE CORRECT DIAGNOSIS TAKES 13 MONTHS FROM THE ONSET OF SPINAL CSF LEAK SYMPTOMS</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #3</p> <p>NOT ALL PATIENTS WITH SPONTANEOUS INTRACRANIAL HYPOTENSION HAVE LOW OPENING PRESSURE</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>csf leak association</p>
<p>LEAK FACT #4</p> <p>SOME PATIENTS REQUIRE A SINGLE BLOOD PATCH TO SEAL A LEAK WHILST OTHERS REQUIRE MULTIPLE PATCHES</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #5</p> <p>SOMEONE SHOWS THAT CONNECTIVE TISSUE DISORDERS SUCH AS EHLERS-DANLOS AND MARFAN ARE COMMON AMONGST SPONTANEOUS SPINAL CSF LEAK SUFFERERS</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #6</p> <p>5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS. 1 IN 20,000 PEOPLE WHOSE CSF PROBLEMS WERE RESOLVED BY THE USE OF CASTLEFORD BRAINTREE RAMSGATE</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>Upright headache? Think CSF leak!</p>
<p>LEAK FACT #7</p> <p>5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS. 1 IN 20,000 PEOPLE WHOSE CSF PROBLEMS WERE RESOLVED BY THE USE OF OLANBASTINE CONSERVING SURGERY</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #8</p> <p>5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS. 1 IN 20,000 PEOPLE WHOSE CSF PROBLEMS WERE RESOLVED BY THE USE OF CAERPHILLY WENTHUR TYDFUL LLANELLI</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #9</p> <p>THE AVERAGE AGE TO HAVE A CSF LEAK IS 46 YEARS*</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>Find out more about cerebrospinal fluid leaks www.csfleak.info/findoutmore</p>
<p>LEAK FACT #10</p> <p>MORE WOMEN THAN MEN HAVE A CSF LEAK 65.7% OF WOMEN 34.3% OF MEN*</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #11</p> <p>Spinal CSF leaks reoccur in 10% of people*</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>LEAK FACT #12</p> <p>The location of a spinal CSF leak is undetectable in 50% of patients*</p> <p><small>Cerebrospinal fluid leaks are not rare!</small></p>	<p>facebook.com/csflakeassociation @csfleakinfo www.instagram.com/csflakeassociation www.csfleak.info</p>

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[Click here to complete our Leak Week Survey](#)

Why not tell us about your own Leak Week highlights? What did we do right? What would you like to see more of? As always, we are grateful for your feedback. Click above to take our very short survey, comprising of six short questions.

THANK YOU FOR SUPPORTING LEAK WEEK 2018!



Are you an existing member whose annual membership is about to expire? Perhaps you've been meaning to join up for a while but haven't managed to yet? Or maybe you know somebody that would appreciate a membership as a gift?

We rely solely on the generosity of our supporters, members and fundraisers to keep things ticking over at the CSF Leak Association, so please don't forget to join up or renew your membership to keep up to date with the latest news and developments, as well as benefiting from a free gift when you renew! To renew your membership, please click [here](#).

To read more about the benefits of becoming a member and to join us, please see our membership overview by clicking [here](#).



Name: Robert Edwards

Type of Leak: Spinal

This edition sees Rob Edwards take his place under the Leaker Spotlight in order to share his story. Thank you Rob!

It took six months for my CSF leak to be diagnosed, but given what had happened in those six months, this was still an inspired diagnosis given the issues fellow leakers have witnessed in being diagnosed. For me it all began at the end of 2016, quite probably with just a big sneeze!

I'd had a very, very bad cold which progressed to my chest and as January 2017 arrived I found every time I coughed or sneezed I got an intense, but transient headache. These headaches progressively got worse, not helped by a few hours at the end of January spent out in the cold on Tring reservoirs doing some bird watching. After that my hearing suffered and the headaches got worse so this prompted my first visit to my GP. Possible sinusitis was diagnosed but after two weeks of anti-biotic medications during February 2017 the headaches remained, although thankfully the worst of my hearing issues went away.

I thought all would get better with some late winter sun and so we spent a week in the Caribbean, but unfortunately the headaches just became stronger and more frequent, and this was when I started having to take regular painkillers to try to ease the pain. There seemed to be no particular pattern to the headaches, nor did they always dissipate when I lied down, although at that time I had no idea of the importance of this. That said, the relevance of this question was never raised by anybody.

Back in the UK I was referred to a neurologist who arranged for an MRI scan, and perhaps stupidly within a couple of hours of the scan, I was ignoring numerous "no caller ID" calls to my mobile. The next morning I had a message from my neurologist saying he'd been calling and asking me urgently to make contact. At this stage I was getting pretty agitated!

Whilst I was trying to find the right number, my neurologist called again and this time I obviously took the call. As he put it, the good news was that I didn't have a brain tumour – but the bad news was that I'd had a massive subdural haematoma. I was actually taking

some blood thinner medication at this time which undoubtedly aggravated the bleed. I came off these immediately. The MRI scan showed the blood to be 1cm deep and the bleed was across my entire brain. Thankfully the neurologist was confident the worst had passed and referred me to a neuro-surgeon given there appeared to be a choice between draining the blood (a burr hole procedure) or letting it be reabsorbed over time. At least we all thought we knew why I was getting headaches.

I agreed with my neuro-surgeon that an operation was the better option and so at the end of April I had the burr hole procedure to drain the blood. There was always a risk that the recovery from this could trigger a further bleed, and a subsequent MRI confirmed that has in fact happened. My headaches had returned within a few days of the operation so I had feared the worst. So I had a second burr hole operation – which then led to a third bleed... At this stage I decided that I did not want any more operations and I would let the bleed be reabsorbed. All this time I was still getting headaches every day and I was taking various painkillers including codeine and oromorph. I was able to get out and about during the day, but mornings and evenings were terrible, with my spending several hours resting. We were now in June 2017, and follow up CT scans and MRI scans were showing the haematoma wasn't being reabsorbed at the rate expected and my neuro-surgeon took a fresh look at all the evidence, including the fact that my headaches started before the first haematoma. He then diagnosed that in all likelihood I'd had a spontaneous CSF leak.

It was a relief to know exactly what my medical problem was, but this soon turned to concern as I read up about the condition, and read online about fellow leakers' experiences. I was settling in to a regime of headaches and now knowing that lying down should get rid of them, I could start to manage the pain. I was on steroids for a short while but I reduced the dosage and soon came off these totally given the risks, but equally I decided to avoid the opiate based painkillers, relying only on standard headache painkillers. They couldn't get rid of the headaches but with resting, they could allow me to get out and about in the middle of the day without any nasty headache. All I now take is a low dosage beta blocker. There was always a "feeling" in my head which I was learning to live with and using to recognise when a headache was going to start.



Certainly my intense headaches started soon after I got up in the morning, and rest for maybe an hour after breakfast often reduced these to a tolerable level for several hours. It was usually early evening that the headaches returned, this time more at the back of the neck and aggravated by movement of the head and spine. As ever, resting eased the pain, but only for an hour or so. It meant that I simply couldn't go out in the evening unless it was somewhere with a bed to lie on close to hand. We live outside London but often travelled in to see my two daughters and friends who live there. This travelling had stopped earlier in the year and remained impossible, as it still is now.

We had to cancel all holidays since I was advised it was unsafe to fly with the remaining haematoma, even if somehow I could manage the pain in transit.

The hunt was now on for the source of the leak, and over the summer months I had two full head and spine MRI scans and a CT myelogram, but the leak could not be found.

A possible blood patch had been discussed earlier in the year but given I had quite a lot of blood under the dura because of the three haematomae, the emphasis was on trying to find the leak for surgery. Over time as the options for finding the leak were running out, we decided to go for a blood patch and I had my first one last November. This gave short term immediate relief from the low pressure headaches (as did the CT myelogram), and I was able to go on a barging holiday and drive to see friends. But after two and a half weeks, the low pressure headaches returned, and with them my usual daily routine. I arranged a second blood patch for February. Amazingly in January the headaches totally went away for a couple of weeks and I was considering cancelling the second blood patch, but the headaches returned, and with them my restricted social life.

As I write this I've just had my second blood patch, but it's only been a week and in the evening I'm starting to get what I think are low pressure headaches once again. I am

hoping that after several blood patches I may be healed, but time will tell.

One piece of good news is that the last haematoma has now all but gone and so I can fly again, although I've not tested this yet. At the moment our foreign holidays are cruises which start and end in the UK, and it's weird, but as soon as I leave the UK heading south, my headaches improve hugely – only to return as I approach the UK again. I cannot tell if this is a change of lifestyle or some aspect of latitude. Maybe this will become clearer as I travel more in 2018!

Until then I live with the headaches, knowing that for many people they are an awful lot worse.



In case you missed it, the focus of Leak Week Day 5 was on Aftercare, and we launched a brand new post-card sized guide outlining some precautions to be mindful of following an Epidural Blood Patch.

The most common intervention to resolve a CSF leak that hasn't resolved on its own accord, is an Epidural Blood Patch. Many of you have told us that there is so little information or guidance available in terms of sensible steps to take following an EBP.

Whilst it is important to note that there are no definite right or wrongs when it comes to what you should, or shouldn't do following a blood patch, nor a definite time frame to follow precautions after the procedure, we have produced a new resource in the form of a postcard highlighting some of the key precautions to consider following a patch.

You must always still consult with your doctor, however. It is also worth noting that blood patches can sometimes fail for unknown reasons, regardless of how rigidly you have followed the precautions, so they are not a guarantee to success. The postcard, 'If In Doubt, Wait It Out!' was produced in consultation with doctors on our Medical Advisory Committee, who all agree that there is still much to learn about leaks and patches, and what works and what doesn't, but by following this advice, as best you can, you are certainly working hard to promote healing.

If in doubt, Wait it out!

csf leak association

Things to try to avoid after an epidural blood patch

Produced in consultation with UK neurologists

WHAT IS AN EBP?
An epidural blood patch (EBP) is a surgical procedure where a patient's own blood is injected into their epidural space in order to close one or more holes in the membrane around the spinal cord. The holes cause a leak of the cerebrospinal fluid (CSF).

- LIE FLAT**
if possible lie flat for at least 24 hours with only short breaks to use the bathroom
- AVOID STRAINING**
for at least 6 weeks!
- AVOID BENDING, TWISTING OR STRETCHING**
for at least 6 weeks!
- AVOID COUGHING OR SNEEZING**
if you must, don't cover your mouth or hold your nose
- AVOID ANTI INFLAMMATORIES**
some doctors recommend that you do not take anti-inflammatories for 7 days
- AVOID CAFFEINE OR SALT**
caffeine and salt can increase CSF pressure, so may worsen any rebound intracranial hypertension, which could 'blow' a blood patch
- AVOID LIFTING**
anything over 5lbs/2.5kg, for at least 6 weeks!
- TRAVEL**
Where possible after a blood patch, avoid driving yourself home. Try to recline or lie down and avoid taking public transport

REMINDER!
These are just a few of the precautions to take after an epidural blood patch.
Please make sure that you always seek and follow professional advice from your doctor.

Find out more about cerebrospinal fluid leaks
www.csfleak.info/findoutmore

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You can download more copies of the postcard by clicking [here](#)

csf leak association

We attended today's reception at the Scottish Parliament to discuss provision for CSF leaks and other rare diseases



RARE DISEASE UK

The Scottish Parliament
Pàrlamaid na h-Alba

www.csfleak.info/findoutmore

The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC0046319)

Rare Disease Day 2018, Scottish Parliamentary Reception

By Deborah Ogg

I was very excited to attend the Scottish Parliamentary Reception for Rare Disease Day. The reception was organised by Rare Disease UK / Genetic Alliance UK and the Scottish Cross-Party Group* (CPG) for Rare, Genetic and Undiagnosed conditions.

Although getting there, being there and recovering was challenging to say the least, it was very worthwhile. I was wearing two hats that evening, one for CSF

leaks, the other for hEDS (Hypermobile Ehlers Danlos Syndrome).

While congregating in the lobby, there was a chance to meet and mingle with each other, share information and push our causes and concerns.

Having to lie flat in public spaces is very advantageous in engaging people's attention and curiosity!

I was able to discuss CSF leaks and hand out our leaflets to many people before we were invited into the hall. Once in the hall, I was able to put our information leaflets and posters on tables provided and talk a bit more about our Rare Disease.

There were great speakers lined up:

Jayne Spink, Chair of Rare Disease UK and CEO of Genetic Alliance UK was able to explain the event, the organisation's involvement and the support they can offer charities and individuals.

Professor Zosia Miedzybrodzka, Professor of Medical Genetics, University of Aberdeen talked of the 100,000 Genomes Project and NHS Scotland's role in working towards genome testing in all rare disease patients. She talked of the strategies needed to make genome testing standard care in Scotland and expand other genetic tests to deliver personalised care. This is already planned in England and Wales, although in all of the UK it will be a long time before it's realised and available.

Shona Robison MSP, Cabinet Secretary for Health and Sport was someone I was keen to hear from and to try to speak to afterwards as I know some Scottish Leakers have already spoken with her in the past. Unfortunately, she was regrettably unable to attend at the last minute which was a real shame for all. Maureen Watt MSP for Mental Health was able to stand in but it was disappointing to hear her speak of the need for a Government initiative 'to help patients understand their diagnosis and treatments' - unfortunately this was not received well at all!

The speakers who really made an impact were, unsurprisingly, the ones with the most experience of day to day life with rare conditions.

Arlene Smyth, Executive Officer, Turner Syndrome Support Society (TSSS) has a daughter with Turner Syndrome. She started TSSS in 1999 and has a wealth of experience and knowledge, not just about Turner Syndrome but in all aspects of raising awareness and lobbying for change where necessary. Her drive and passion extend to all those with rare conditions who need more support and better healthcare. Arlene understands the importance of coordinated care and is unrelenting in her drive to see Specialist Nurses for Rare Conditions in the NHS. She talked of what these nurses could offer in terms of information, reassurance, support and coordination of care for patients. They would be an invaluable lifeline and a value for money resource within the NHS. She intends to make this happen!

Professor Faisal Ahmed, Project Lead, Office for Rare Conditions (Glasgow) It was refreshing to hear of this exciting new office to help diagnose and treat children with rare conditions. The professor was candid and spoke of how sharing of expertise between colleagues and coordinated care just does not

happen and that there is little opportunity to do this currently within NHS set ups. He spoke of how colleagues were simply not aware of many rare conditions and that there were none of his colleagues present that evening. He highlighted the need to address gaps encountered by patients, parents and health care professionals at the coal face. The common issues being, to increase awareness (both public and NHS), support needed, clinical pathways needed, patient advisory groups needed and participation of patients in research.

The Office for Rare Conditions is aimed at addressing these gaps in expertise and care and could lead to similar programs around the UK.

Rebecca Pender, mother of Hannah who has a condition called Inverted Duplication / Deletion Syndrome 8p. There are only 65 registered cases worldwide. Although Hannah's condition is extremely rare, Rebecca's presentation was all too familiar to many ears. It was heart breaking to hear of the familiar struggles, doubts, battles, brick walls and absence of knowledge and care. Her honesty hit all of the audience and made a real impact on everyone. There were tears shed and hands over gasping mouths. Especially from those who don't have direct experience of a rare condition, such as MSPs and councillors in attendance. Doctors and nurses were able to hear it again and the reinforcement worked. Her standing ovation was well deserved.

After the speakers there was another networking session and I had a chance to speak with some people from Genetic Alliance UK. They were very interested to hear of my own timeline of leaking and how I ran a crowd funding campaign to get treatment abroad. Even more so when I told them that many CSF leakers have paid for private treatment both in the UK and overseas. This may be something they follow up on... watch this space!

It was a great event and one which I hope to attend again.

There is a lot of work going on by individuals, quietly beavering away and when gathered together it absolutely feels like we are stronger.

What I took from the evening was - there will always be a need to raise public and medical awareness of Rare Conditions.

However, to make things happen in terms of diagnosis, treatment and support, we don't need to engage everyone in our cause, and really, we don't want to engage with those who don't care. It's the people who are passionate and the ones with drive who make things happen. That evening, meeting people who are passionate, those taking to the stage and in the audience, provided another network to learn from, work with and gain support from and to help the CSF Leak Association and us 'leakers' just a little bit more.

*Cross-Party Groups (CPGs) provide an opportunity for Members of Parliament of all parties, outside organisations and members of the public to meet and discuss a shared interest in a particular cause. Scottish, Welsh and English Parliaments each have their own CPGs.

* MSP is a Member of Scottish Parliament – same as an MP in England.



We are on the hunt for willing volunteers to join our Focus Groups - in particular Cranial Leakers and Friends and Family Members of CSF leak sufferers (current or former).

We are a membership organisation and an organisation run entirely by volunteers; people are at the heart of the CSF Leak Association.

To compliment our future projects, we are looking for expressions of interest from UK residents for membership of our new focus groups. The groups will look at different aspects of our work and aims, such as new and reviewed publications and website content prior to it being published.

An expression of interest does not commit you to joining a group nor does it obligate us to select you for any specific group; different groups will be established for different purposes, so we'll try to match groups with people's interest and background as best as we can.

Focus group members would be expected to be involved for a minimum of a year. Membership will involve a bit of reading and feedback through email correspondence and Skype calls, but should not be onerous. As all of our trustees have experience of CSF leaks, we appreciate the need to be flexible and respond to health limitations.

Please contact us via volunteer@csfleak.info to register your interest.



We are currently looking for volunteers to assist with co-ordinating fundraising for the CSF Leak Association and also to moderate an online community.

If you have experience or an interest in either of these areas please drop us a line at volunteer@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

If you've not already found us on Instagram, why not visit our page & follow us today?

Follow us on
Instagram

[instagram.com/csleakassociation](https://www.instagram.com/csleakassociation)

The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC0046319)

Did you know that during Leak Week we launched our Instagram account? Head over and follow us - and link your photos and images with the hashtags - which you can also follow on Instagram!



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

We have prepared an alphabetical list of some of the most commonly used CSF Leak terminology on our website. Below is some of the terminology that start with G through to N. We will share further terminology in future editions.

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.

Intracranial Hypotension

A loss of CSF (normally through a tear or absorption) greater than its rate of production leads to a decreased volume inside the skull. This is known as intracranial hypotension.

Lumbar Puncture

A lumbar puncture is a diagnostic medical procedure. It is used to collect and measure the pressure of cerebrospinal fluid (CSF) and to confirm or exclude conditions such as meningitis and subarachnoid haemorrhage.

The procedure is typically performed under local anaesthetic and aseptic technique. A needle is used to access the subarachnoid space and fluid collected. Fluid may also be sent for biochemical, microbiological and cytological analysis.

A lumbar puncture is generally regarded as a safe procedure, but is not without risk. Risks can include additional CSF leaks, nerve damage, infection and epidural haemorrhage.

Magnetic Resonance Imaging / MRI

Magnetic resonance imaging (MRI) is a medical imaging technique used to investigate the anatomy and physiology of the body. MRI scanners use strong magnetic fields and radio waves to form images of the body. The technique is widely used in hospitals for medical diagnosis, staging of disease and for follow-up without exposure to ionising radiation. MRI imaging is sometimes used in combination with IV or intrathecal contrast, such as gadolinium.

Meninges

Intrathecal

Intrathecal refers to something occurring in or introduced into the anatomic space or potential space inside the arachnoid membrane of the brain or spinal cord (under which is the subarachnoid space).

Intrathecal Contrast

A contrast agent injected into the cerebrospinal fluid to better visualise the spinal canal and nerve roots in the spine. Where it leaks out with the dura, it may indicate the location of a CSF leak.

Lumbar

The lumbar region, sometimes referred to as the lower spine, comprises the five vertebrae in the lumbar region of the back (L1-L5) that are the largest and strongest in the movable part of the spinal column. The lumbar region of the spine curves outward.

The lumbar portion of the spine bears the most body weight and also provides the most flexibility, a combination that makes it susceptible to injury and wear and tear over time.

The spinal cord does not descend far into the lumbar region; for this reason, and in order to reduce risk, it is the normal location for lumbar punctures and high volume epidural blood patches.

The meninges are the membranes that envelop the central nervous system. They consist of three layers: the dura mater, the arachnoid mater, and the pia mater.

Nerve Root

Nerve roots are bundles of nerve fibres, the initial segment of a nerve leaving the central nervous system. Types include:

- A cranial nerve root, the beginning of one of the twelve pairs leaving the central nervous system from the brain stem or the highest levels of the spinal cord;
- A spinal nerve root, the beginning of one of the thirty-one pairs leaving the central nervous system from the spinal cord. Each spinal nerve root consists of the union of a sensory dorsal root and a motor ventral root. At the height of each intervertebral space of the spinal roots go four – two roots ventral and two dorsal roots, one pair of right and left side of the core.

You can view our full A to Z of terminology on our website, or download it in PDF format by clicking [here](#).



Head on over to our merchandise shop at www.csfleak.info/shop/ Where you will find a fabulous selection of useful items and clothing. Each sale raises a small amount for the CSF Leak Association, and can help to spread awareness. Merchandise can be used for sporting activities or fundraising events, given as gifts, or even a treat to yourself! Wristbands and button badges can be given as wedding favours and mugs donated to clinicians. The options are endless!

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Please send over your 'mug shots' to us at newsletter@csfleak.info



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


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

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

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