CSF Leak Association Newsletter | Issue No.6 | Autumn 2017

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Message from the Editor

Hello, <<First Name>>.

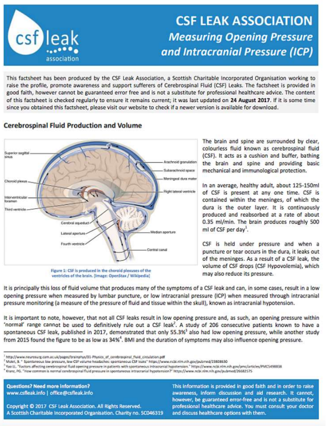
Welcome to the sixth edition of Leaker Life. In this edition, please expect to find lots of useful and important information about CSF leaks, and also some interesting articles regarding EDS and CSF leaks.

Of particular interest is the attention that CSF leaks have received in the media of late - a huge victory for us all!

We have also included a survey and would be extremely grateful if you would spare a few minutes to tell us your thoughts about the work we are doing, and if we are missing anything.

Work continues to progress well with the development of our Medical Advisory Committee. Watch this space for news on that front.

The first ever Intracranial Hypotension Symposium took place on 14th October in California. We start to report on that in this edition, but expect more in later newsletters.



CSF LEAK ASSOCIATION
Measuring Opening Pressure and Intracranial Pressure (ICP)

This factsheet has been produced by the CSF Leak Association, a Scottish Charitable Incorporated Organisation working to raise the profile, promote awareness and support sufferers of Cerebrospinal Fluid (CSF) Leaks. The factsheet is provided in good faith, however cannot be guaranteed error free and is not a substitute for professional healthcare advice. The content of this factsheet is checked regularly to ensure it remains current; it was last updated on **24 August 2017**. If it is some time since you obtained this factsheet, please visit our website to check if a newer version is available for download.

Cerebrospinal Fluid Production and Volume

Figure 1: CSF is produced in the choroid plexuses of the ventricles of the brain. [Image: OpenStax / Wikipedia]

The brain and spine are surrounded by clear, colourless fluid known as cerebrospinal fluid (CSF). It acts as a cushion and buffer, bathing the brain and spine and providing basic mechanical and immunological protection.

In an average, healthy adult, about 125-150ml of CSF is present at any one time. CSF is contained within the meninges, of which the dura is the outer layer. It is continuously produced and reabsorbed at a rate of about 0.35 ml/min. The brain produces roughly 500 ml of CSF per day[1].

CSF is held under pressure and when a puncture or tear occurs in the dura, it leaks out of the meninges. As a result of a CSF leak, the volume of CSF drops (CSF Hypovolemia), which may also reduce its pressure.

It is principally this loss of fluid volume that produces many of the symptoms of a CSF leak and can, in some cases, result in a low opening pressure when measured by lumbar puncture, or low intracranial pressure (ICP) when measured through intracranial pressure monitoring (a measure of the pressure of fluid and tissue within the skull), known as intracranial hypotension.

It is important to note, however, that not all CSF leaks result in low opening pressure and, as such, an opening pressure within 'normal' range cannot be used to definitively rule out a CSF leak[2]. A study of 206 consecutive patients known to have a spontaneous CSF leak, published in 2017, demonstrated that only 55.3%[3] also had low opening pressure, while another study from 2015 found the figure to be as low as 34%[4]. BMI and the duration of symptoms may also influence opening pressure.

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[1] http://www.neurosurg.cam.ac.uk/pages/brainphys/01-Physics_of_cerebrospinal_fluid_circulation.pdf
[2] Mokri, B. " Spontaneous low pressure, low CSF volume headaches: spontaneous CSF leaks" https://www.ncbi.nlm.nih.gov/pubmed/23808630
[3] Yao LL. "Factors affecting cerebrospinal fluid opening pressure in patients with spontaneous intracranial hypotension." https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5498838
[4] Kranz, PG. "How common is normal cerebrospinal fluid pressure in spontaneous intracranial hypotension?" https://www.ncbi.nlm.nih.gov/pubmed/26682575

Questions? Need more information?
www.csfleak.info | office@csfleak.info

A Scottish Charitable Incorporated Organisation. Charity no. SC046319

Measuring Opening Pressure and Intracranial Pressure.

You can now download our updated publication: *Measuring opening Pressure and Intracranial Pressure (ICP)* by clicking here.

The factsheet covers different ways of measuring ICP, Intracranial Pressure Monitoring, and Measuring Opening Pressure via Lumbar Puncture.

Remember, also, our overview leaflet, which has

In the meantime, thank you for your ongoing support. We hope that you enjoy the newsletter!

Polly Walker
Editor

been produced in consultation with UK neurologists, Dr Simon Ellis and Dr Manjit Matharu, available here.

All of our factsheets and leaflets are ideal for downloading, printing off and taking with you when you visit your doctor.

The headache that changed my life

3 October 2017 | Scotland

David Baldwin developed CSF leak more than four years ago

CSF Leaks hit the media in October 2017...and gained quite a bit of attention!

Did you hear our Chairman, David Baldwin's interview on the Kaye Adams Show, Radio Scotland, on Tuesday October 3rd?

If you missed it, fear not, you can listen here:

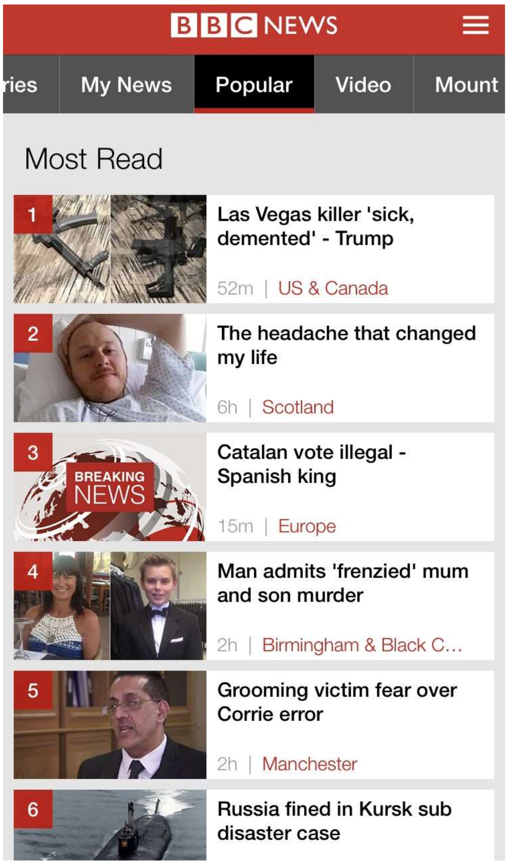
Click here to listen now

Congratulations to David, who gave an incredibly informative and interesting interview, and of course to the many fellow leakers that contacted the show to share their stories and to show their support.

Hearing Kaye share her own personal experience of a CSF Leak was quite remarkable.

As a result of the interview, an article was featured in the BBC News App 'The Headache that Changed my Life', and it certainly seemed to attract quite a lot of interest, reaching number 2 in the most read articles that day!

You can read the full article by clicking here.



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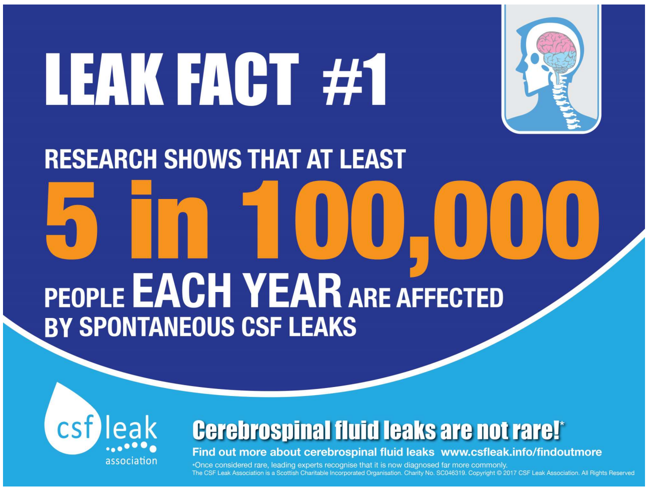
David then went on to feature on a short news piece on BBC Scotland on the 4th October. You can watch it here.



LEAK FACT #1

RESEARCH SHOWS THAT AT LEAST

5 in 100,000

PEOPLE **EACH YEAR** ARE AFFECTED BY SPONTANEOUS CSF LEAKS

csf leak association

Cerebrospinal fluid leaks are not rare!*

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

*Once considered rare, leading experts recognise that it is now diagnosed far more commonly.

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Did you know?

Look out for our brand new eye catching bite-sized leak facts.

Please like, share and remember to include the hashtags:

#csfleak

#spinalCSFleak

#uprightheadache

We would like to extend a very warm welcome to our newest Trustee, Clare Joy.

Clare has lived with a hypermobility syndrome and POTS for many years before becoming a spontaneous leaker in October 2015. Along her leak journey she has also developed migraine and trigeminal neuralgia, and continues to suffer daily leak symptoms despite blood patches and surgery - although thankfully not to the same extent or intensity. She has decided to focus on what she can do now, that she couldn't do whilst flat. She is grateful for the opportunity to advocate for those of us who so often feel isolated and voiceless. She hopes to use her skills developed in her career to further the charity's aims.

Clare is a clinical scientist working in Medical Physics in the NHS. She lives in Southampton with her husband and loves to be distracted by all things craft and sewing related.

We are all very excited to have Clare on board!

The Importance of Patience and Gentle Persistence

by Lisa Jamieson, Research Fellow, The Wingate Institute of Neurogastroenterology, Barts & The London School of Medicine and Dentistry, Queen Mary University of London.

Lisa Jamieson began her career working in community pharmacy before moving into medicines management and then NHS planned care service redesign. She set up her own healthcare consultancy business while studying for an MSc in Nutritional Medicine. In 2014, after developing a spontaneous cerebrospinal fluid leak, Lisa was subsequently diagnosed with hypermobile Ehlers-Danlos Syndrome. With a lack of published evidence to guide her, Lisa tried to figure out for herself how she might improve her health. She decided to experiment with her diet and nutrition, which had unexpected positive consequences.

In her talk at the Genetic Disorders UK Leadership Symposium in Spring 2017, entitled "The importance of patience and gentle persistence", which you can listen to by clicking the link below. Lisa talks about how her sudden illness led to her discovering a new way of managing the symptoms of her hypermobile Ehlers Danlos syndrome (hEDS). Lisa now works as a part-time research fellow at The Wingate Institute for Neurogastroenterology and at The Royal London Hospital, where she is studying the impact of dietary changes on other patients with hypermobile Ehlers-Danlos syndrome.

Listen to Lisa's Presentation Here

We had an article featured in the May edition of Fragile Links (EDS Support UK's Quarterly magazine) discussing the links between EDS and CSF leaks. This is repeated below.

By CSF Leak Association Trustee, Deborah Ogg

The Ehlers Danlos Syndromes and Hypermobility Spectrum Disorders are little known in the world at large and to add to the difficulties that causes, those of us with EDS and HSD are more likely to develop a number of additional conditions which can seem even more rare and misunderstood. One of these medical mysteries is Spontaneous Intracranial Hypotension (SIH) also known as a CSF leak (cerebrospinal fluid leak).

CSF leaks can be extremely debilitating and life limiting. There is no escape from the crushing pain and symptoms and many sufferers exist horizontally, unable to be upright for any length of time. Diagnosing and finding spontaneous leaks can be challenging as there are few experts in the world.

It is well known within the EDS community that ligaments, tendons, vascular structures and organs, skin and bones can be weak because of poor collagen in our tissues. However, there is a structure protecting our central nervous system, spinal cord and brain which is also at risk. The Dura Mater. The Dura is a leathery skin surrounding the brain and spinal cord. It holds a liquid called Cerebrospinal Fluid (CSF) which bathes these delicate areas, cushioning them from knocks and bumps and keeps the brain afloat. It also feeds these vital body parts and takes waste away. The dura is made up of quite a few types of collagen, it is a very flexible and elastic structure and is also very strong. It has to flex and stretch as we move and when the dura isn't in tip top condition there is a risk of it tearing or becoming damaged. For most people who spring a CSF leak, it will heal itself in days to weeks. For some it takes months. For those with a connective tissue disorder it can take years, if it heals at all, and they may develop new leaks throughout their life. A leading CSF leak specialist, neurosurgeon Dr Wouter Sheivink (Cedars Sinai, LA) has surgically treated more CSF leaks than anyone else and states that over 99% of spontaneous leaks occur in those with some form of connective tissue problem.

The link between CSF leaks and connective tissue disorders is already recognised by some of the EDS experts we know of and for many sufferers, a CSF leak is the first major presentation of EDS. So far it seems that the most common co morbidity is spinal CSF leaks in those with hEDS. However, as with most ‘other issues’ in EDS, the link is not proven and more research needs to be carried out.

It's important for those of us with EDS and HSD to be aware of the increased risk of damage to the dura, the symptoms to recognise and to know the types of medical procedures to potentially cause trauma in this area. We are less likely to heal well and when a CSF leak becomes chronic, it also becomes more difficult to treat.

LUMBAR PUNCTURE & SPINAL ANAESTHETIC

Some of you may have had lumbar punctures or a spinal anaesthetic and may have experienced a Post Dural Puncture Headache. This is caused by cerebrospinal fluid leaking from the site where the needle went into the dura to take CSF samples or inject anaesthetic.
The best way to avoid problems after these treatments is for the doctor performing the procedure to use a specific type of needle. An atraumatic, pencil tip or non-cutting needle of a small gauge is best. This type of needle will part the fibres of the dura rather than cutting into them. The higher the number of the needle, the smaller it is (a 22 gauge needle is smaller than an 18 gauge).

EPIDURAL ANAESTHETIC & SPINAL NERVE BLOCKS / FACET INJECTIONS

These procedures are not supposed to pierce the dura and should be performed just outside it. However, we are talking millimetres of difference and mistakes happen. Often after epidural for childbirth there is so much else to attend to, that the symptoms go unnoticed at first. Symptoms can appear weeks after the procedure.

SURGERY

There are many risks associated with cranial and spinal surgery. As with the above procedures, CSF leaks will be mentioned on the medical consent forms but are usually downplayed by medical professionals. Most don't have any experience of leaks becoming chronic and have no idea how debilitating they can be. If a surgeon is aware of cutting the dura by mistake, you may not be told about it because in most cases, a CSF leak is considered to heal itself. As you know, those with connective tissue problems don't heal so well, so that's often not the case with us.

If you have EDS or HSD and are having these procedures, you should make your doctors aware that you may be at increased risk of a CSF leak.

Other causes of CSF leaks include trauma such as car accidents or falls and bone spurs piercing the dura - those of us with hypermobile spines, degenerative disc disease and spondylolisthesis take note.
Intracranial Hypertension and IIH (too much CSF causing increased pressure in the skull due to CSF not draining properly) can cause both cranial and spinal CSF leaks as the increased pressure 'blows a leak', wears down the bones of the skull base or thins the spinal dura. Skull base irregularities can also lead to cranial CSF leaks. Acquired Chiari can occur with spinal CSF leaks - due to a lack of fluid, the brain cannot float and it slumps into the skull base, showing 'brain sag' and tonsillar descent. Once repaired, the brain lifts and is positioned normally.

SYMPTOMS of a Spinal CSF Leak

The most common symptom is a headache which is usually postural. It will come on or get much worse when you sit or stand. It can be severe and frightening. It is usually felt at the back of the head but not always. It is usually felt on both sides of the head. Often there will be other symptoms involved from the list below:
A feeling of pressure within the skull, a sense of your brain being sucked down into your neck, sensitivity to light and noise, nausea and vomiting, tinnitus, blurred vision, vertigo and balance problems, neck pain and stiffness, pain between the shoulder blades, numbness, tingling or weakness in arms or legs, facial pain or numbness, brain fog and memory problems, no ability to concentrate. Sometimes, a chronic spinal CSF leak can mimic POTS or exacerbate symptoms in those who have it.
The biggest clue to diagnosis is that all of the above symptoms usually get better when lying flat.
A spinal CSF leak is usually diagnosed by a neurologist, as the most common first

presentation is headache which is worse upon being upright. Due to the clinical terminology 'headache', the pain is usually underestimated by most. Over the years there has been little to no research carried out due to it being seen as a 'headache' syndrome and classed as a benign condition.

TREATMENT for spinal CSF leaks usually involves strict bed rest, increased hydration and caffeine as the first step. If this fails, an IV caffeine infusion is often tried, though this has shown limited success in most patients. The standard treatment is a Blood Patch, where blood is drawn from your arm and injected into the epidural space, just outside the dura. This is thought to start a healing process causing scar tissue to mend any tears or holes in the dura. It often takes a few patches before relief is found. It seems a simple fix but if the location of the leak is unknown, this procedure is less likely to be a success. Finding spontaneous CSF leaks is a very tricky process.

SYMPTOMS of a Cranial CSF leak

The most common symptom is seeing or feeling the fluid drip out of the nose or ears. Sometimes it can leak through the eyes. CSF usually leaks from just one side, however it can leak from both left and right sides. Fluid can also drip or run down the back of the throat. It tastes metallic and can cause a sore throat. The fluid will drip faster or sometimes gush out when you bend forward, strain or lie down. Headaches are less common but they do occur. Pulsatile tinnitus is common. With cranial leaks, there is an open route from the outside world into the brain and a real risk of contracting meningitis. It's important to get a diagnosis and repair the leak.

Cranial CSF leaks are often mistaken for allergies and people are sent to an ENT specialist. Testing the fluid which drops or pours out of your nose, ears or throat is a tricky task as it must be handled in a specific way and tested within hours. Do some research and give the protocols to your consultant to enable them to carry out the tests for you.

TREATMENT for cranial leaks depends on where the leak originates. Some repairs to the skull base can be done endoscopically through the nose, other leaks may need a craniotomy, where the skull is opened and the dura repaired inside. These are usually very successful procedures.

Most people who experience CSF Leaks will have either a cranial or a spinal leak. It is not usual to have both, however it is not unheard of.

At present, CSF leaks are similar to EDS in that even the specialists you are seen by don't know much at all about the condition or have little experience treating it. As with EDS, being knowledgeable can make some doctors wary of you and label you as a hypochondriac. It can be frustrating, scary and lonely. However, there is much more information and advice available online than there was as little as 2 years ago. There are a few Facebook support groups and 2 charities set up to inform, educate, raise awareness and support those affected by the condition. The UK charity, The CSF Leak Association has information which you can download and take to your GP and consultants (these have been approved by experienced neurologists in the U.K.) and the charity is there to support anyone affected by CSF leaks.

You can find more information on CSF leaks and Spontaneous Intracranial Hypotension (SIH), symptoms, tests and treatments from The CSF Leak Association www.csfleak.info.

Please take part in our survey - we are keen to hear your thoughts about the work we're doing and to identify the areas that we need to improve on. This is the first of number of surveys to be compiled over the coming year, and is considered a general survey that will help to inform others.

Click *here* to take part. It is an anonymous survey and will take less than 5 minutes!

Please have your membership number to hand if you are a member of the CSF Leak Association.

With many thanks from us all here at the CSF Leak Association.

The first **Intracranial Hypotension Symposium** was held on October 14, 2017. Hosted by **Cedars-Sinai Medical Center** in partnership with **Spinal CSF Leak Foundation**.

The full-day multidisciplinary symposium on intracranial hypotension secondary to spinal cerebrospinal fluid (CSF) leak brought together top clinicians and researchers to share the latest advancements in diagnostics and treatments of this under diagnosed, disabling but treatable secondary headache disorder. Clinicians, researchers and patients were all invited to attend.

The speakers included representation from a range of subspecialties, including neurology, neurosurgery, neuroradiology, pain management/anesthesiology, integrative medicine and clinical genetics.

There was a professional track and a patient/caregiver track. Professional sessions covered current aspects of clinical findings and diagnosis, etiology, diagnostic imaging, percutaneous interventions and surgical approaches. Sessions for patients and caregivers provided an overview and update on the current diagnosis and treatment of intracranial hypotension as well as information to empower patients in improving outcomes and quality of life. Challenging cases were submitted in advance for review and discussion by a team of experts. A panel of clinicians and researchers had a round-table discussion about priorities for research and developments.

We look forward to including further news of the symposium in our next newsletter.

Andrea J. Buchanan is a New York Times bestselling writer. Her memoir about her experience with a spinal CSF leak, 'The Beginning of Everything'. will be published in May 2018 in the UK). Here she discusses the recent Intracranial Hypotension Symposium, which she was able to attend.

So glad I was able to attend the Spontaneous Intracranial Hypotension Symposium hosted by Cedars-Sinai this weekend featuring doctors—and patients—from around the country coming together to share information and new research about this rare condition. I was thrilled to see Dr. Peter Kranz and the team from Duke, where I was successfully treated, and hear their presentations about the ground-breaking work they're doing; also to meet Dr. Connie Deline, co-founder of the Spinal CSF Leak Foundation, and Dr. Wouter Schievink, a giant in the field.

One of the most remarkable things about this conference, to me, was the inclusion of patients and patients' voices. And not just lip-service inclusion: each of the presentation rooms featured individual benches lining the walls, benches long enough and comfortable enough for a person leaking cerebrospinal fluid to lay down, each bench furnished with a pillow. (When I was actively leaking, I evaluated every place I went by the prevalence of flat spaces to which I could retreat if necessary, and in my time I laid on many an uncomfortable floor, or awkwardly

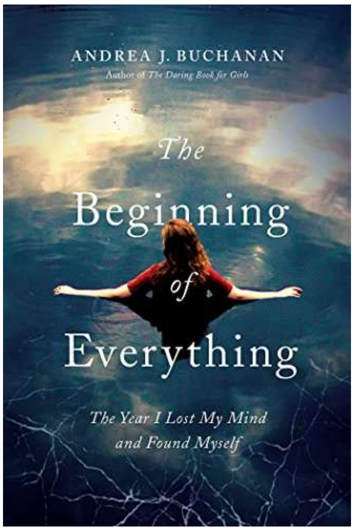
Patients' experiences are often left out of the equation, because they are subjective and hard to quantify; and yet this is important data—in some ways perhaps the most important data. Because even the most subjective description of what it's like to experience symptoms due to treatment or during the recovery process or just from the condition itself is *information*. And information is key, especially in the context of a little-understood disease or condition. It was heartening to see patient information given weight here, whether it was the patient who came to the mic to provide insight to the panel of doctors about a test one physician had characterised as non-invasive and thus not a big deal (which was very much not her experience); or the patient who brought up a concern about fibrin glue patching and the risks of mast cell activation; or, heartbreakingly, the physician who was there as the father of a young patient with SIH who had been treated by many of the doctors present at the conference, representing major medical centres across the country, and asked “What about the people who don't get better?”

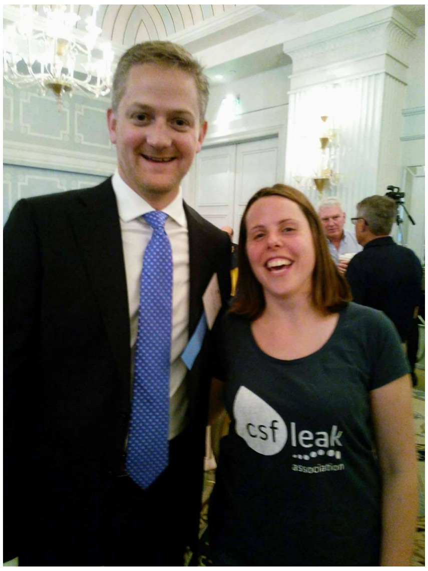
It's a difficult thing to live with uncertainty. For patients, especially, but also for doctors. The uncomfortable experience of uncertainty is limited when certain elements can be excluded—when the data is only about numbers and outcomes and trends and statistics, and not the messy realities of human lives and the way they often thwart tables of carefully sprawled myself across two chairs, or otherwise made a spectacle of myself in my attempts to be flat. So this thoughtful accommodation was much appreciated.)

There was a “patient track” as well as a “clinician track” to the presentations; but there was also opportunity for patients to speak with doctors, one-on-one and as a group, to share their experiences and add some personal reporting to what for many clinicians is a one-sided affair. This kind of information sharing is crucial, especially in the context of a rare disease, because, whether you are a researcher or clinician or patient, the more information that can be gathered from both sides—from the clinical, hard science side of studies and procedures and their efficacies, as well as from the personal reporting from the frontiers of our own pain about how these treatments affect us and our bodies and minds—the more data we have about the full experience of the condition, including what works and what doesn’t, and what those things feel like, and all of those things, in aggregate, help point to a way forward.

calculated findings. So thanks to Cedars-Sinai, the Spinal CSF Leak foundation, and all the doctors and medical professionals working to understand and refine treatments for this condition, for not excluding the data of the real, complex, individual patients who look to you while they get on with the uncertainty of living.

You can pre order Andrea's memoir, 'The Beginning of Everything', by clicking here.





Cerian Baldwin, a Trustee of the CSF Leak Association, attended the symposium. Here she is pictured with Dr. Kranz, Neuroradiologist at Duke Health, Durham, North Carolina (bottom left), Dr. Wouter Schievink, Neurological Surgeon at Cedars-Sinai, Los Angeles (top right) and Connie Deline MD, Vice President & Secretary of the Spinal CSF Leak Foundation to the right of Cerian (bottom right photograph) alongside a number of CSF 'leakers' attending the symposium and showing their support.

We're looking for volunteers to help with our work. Whether you have particular experience or skills that you feel may be of use, or just want to muck in and help with anything that needs doing, we'd love to hear from you. We may not have specific job for you immediately, but we have set up a list of volunteers and we will circulate emails as and when projects arise, initiatives begin etc. to see who's interested and able to assist. If you're interested in volunteering, please email: volunteer@csfleak.info

Dr Manjit Matharu

Development of our Medical Advisory Committee

We are very excited to announce the Medical Advisory Committee (MAC) is developing at speed, with arrangements underway for our the first MAC meeting to take place in early 2018 at the National Hospital for Neurology and Neurosurgery.

Dr Manjit Matharu, Consultant Neurologist and Clinical Lead of the Headache Group, will facilitate this first meeting and has expressed his commitment and enthusiasm for working with the Association.

We look forward to working with the MAC and to keeping you updated with the advancement of our collaboration.

This edition we hand over to Suzanne Morgan who acquired her leak from an epidural injection. Thank you Suzanne for agreeing to share your story with us!

Name: Suzanne Morgan

Age: 39

Hometown: Liverpool

2017 was meant to be the best year I'd ever had – I'd named it 'Year of Completion' on my positive board at work. It was also the year that we would welcome our long awaited son in the world. We had been through a great deal to get to this point, including a long IVF journey that took us to Cyprus. Unfortunately, due to a low-lying placenta, a C Section was planned for me – not the path I could have chosen, and I felt unprepared for it.

Unfortunately there were some issues with getting the needle in when it was time for me to have my anesthetic, to the point that I was told I was so slim that my bones were narrow and the needle couldn't get through. Finally it worked and our baby was delivered very quickly – I cried with joy as I could now start to live as a family as I had longed for for so long.

Unfortunately, my health seems to deteriorate rapidly, I was aware that I was feeling quite unwell and was taken back to the ward, and despite feeling this way, I was still discharged. A severe headache continued, and I returned to the hospital where I was told that I had a spinal headache. I was told that it would be better within 7 days and believing this, I declined a blood patch. Over time the headaches began to clear but I was left with extreme brain fog, full feeling and burning ears, severe dizziness, nerve pain, and all I wanted to do was sleep. I knew something was really wrong.

Thankfully the midwife realised how ill I was and I was admitted back into hospital. Unfortunately, I was then repeatedly misdiagnosed, my MRI was clear, and despite numerous appointments and different medication, I was still unwell. I was missing out on so much of life because I had to lie down the whole time, including a family holiday to Spain. Finally I stumbled across the CSF Leak Association and everything began to make sense. Armed with this knowledge and support, I was finally able to confidently fight my corner and another blood patch was arranged for me. I was unsure about the after care, but again found some very helpful information on the CSF Leak Facebook forum. However, the patch didn’t work and again I was left battling and having to prove what was wrong with me. I suffered tremendously with anxiety and depression as a result of everything I was going through, particularly feeling that I was unable to look after my son.

I am still suffering with symptoms, but I have now found a knowledgeable and fantastic doctor. I now feel validated and that there is hope, and another blood patch awaits me. Whilst I am much better now than I was, I still have very hard days. But I know that it won’t be forever and I will never give up fighting for my health. I won’t lie down and surrender!

Suzanne's young family give her the motivation to overcome her CSF leak.

Don't forget to head on over to our
online shop
at

https://www.csfleak.info/shop/

where you can purchase a wide
range of fabulous merchandise
whilst supporting the charity! Keep
us in mind when you start writing
your Christmas lists....

We're always keen to see our merchandise in action, so please do send us your pictures. And we particularly love to hear news of original ways to fundraise and spread awareness. Donia Whelan recently provided her wedding guests with CSF Leak Association wristbands in lieu of a bridal favour.

What a super idea Donia - thank you and congratulations to you both!

sWhat is it like to have an MRI?

If it is your first step to confirming a suspected CSF leak and you've not experienced an MRI scan before, you might have lots of questions, and possibly anxieties about what it will be like. Here is a break down of what an MRI scan is like, coupled with a few tips!

What is an MRI Scan?

An MRI scan is a Magnetic Resonance Imaging scan. It uses strong magnetic fields and radio waves to take pictures of the brain or spine. It is different to other scans because the images it produces are more detailed.

Before the scan –

You will be asked to answer a number of questions. You may even receive these in the post at the time of your appointment confirmation letter. The purpose of these questions is to ensure it is safe for you to have an MRI scan. There are no risks associated with an MRI scan, however, because strong magnets are used, you will be asked if you have a pacemaker, if you have an artificial heart valve, if you have ever had surgery on your head, if you have any metal implants in your body and also if you have ever had any metal fragments in your eyes from activities such as welding or metalwork.

You will probably be asked to change into a hospital gown, however some hospitals allow you to remain in your own clothes – make sure you wear something loose, comfy, not too warm and without any metal fastenings etc – ladies be aware of underwired bras too! You will be asked to remove any jewellery and items in your pockets. You won't be able to take your phone into the scanning room, and a locker is usually provided for your other items – your bag, keys, coins etc.

Now is a good time to have a trip to the toilet, as you won't be able to go halfway through the scan! Also, tell the radiology nurse if you are anxious about the scan. Many people have concerns about feeling claustrophobic in the scanner. They will be able to reassure you, but also give you some tips for overcoming this.

During the scan

When you enter the room you will be asked to lie on the scanner table. You will be asked to bend your knees over a small padded cushion. The nurse will probably offer you a blanket and some earplugs or cotton wool to pop in your ears. Then you will be given a set of headphones to put over the top. Many radiology departments will ask if you'd like to listen to music, or the radio, and sometimes you are also asked in advance if you would like to bring your own CD in to listen to. At this point the nurse will also point out a small mirror above your head which is positioned at an angle so that you can see out of the scanner at all times. It will make you feel less enclosed. You will also be given a little round alarm button to hold in your hand to press at any time should you wish to attract the attention of the staff. However, the radiologists will be facing you through the window at all times.

You will be aware if your scan has been planned to include contrast. This is to highlight the blood vessels in your brain or spine in order to produce more detailed images. The dye will be inserted via a cannula. At this point you may have the cannula inserted, usually into either the hand or the arm. You will be given an injection in order to insert the cannula - this is no different to having a blood test injection: "sharp scratch"! The cannula will stay in now until the radiologist is ready to insert the contrast, usually a little way into the scan the process will be paused and the nurse will re enter the room to insert the contrast into the cannula. The cannula is made of plastic and not metal and so is safe to remain in during the scan.

An open, cage like structure will be placed over your face – it does not touch you and is spacious will large gaps to see through.

You will now be ready to move into the scanner. The staff will go out of the room and will continue to watch through the window, and they will also communicate with you via the intercom through your headphones. They will tell you when the scan is about to start and also give you updates throughout about how much longer there is to go. There are also air conditioning fans to keep you cool if it is particularly a warm day, this will also help you to feel less enclosed.

The scan is painless. You won't feel anything. It is very noisy though. To know what to expect the noises to be like, listen at the link below:

What does an MRI scanner sound like?

During the scanning keep as still as possible – any movement will blur the images. This includes coughing, sneezing, swallowing and even moving your eyes around! Each sequence of pictures takes about five minutes and there will be a pause in between for you to shift positions if necessary.

As well as being noisy, the scan can also be very boring.

Our tips are:

Shut your eyes, breathe slowly and deeply and think nice thoughts – imagine you are at a spa, in bed at home, or somewhere nice!

If you are to have an injection of dye, the radiology nurse may reenter the room half way through the scan to insert the dye into the cannula. This will feel cold as it enters your bloodstream, but will otherwise be painless. Following the scan, you might be advised to drink lots of water throughout the day to flush the dye out of your system.

After the scan -

Following the scan you will be free to go home straight away. The radiologist nurse will not give you the results there and then and it is unlikely that they will be able to discuss the scans with you, but they will likely advise when you will receive the results and how they will make their way to you.

Tractor RALLY 2017

BLACK ISLE SHOWGROUND 23rd SEPTEMBER

Join us for a fun filled event in aid of the **CSF Leak Association** raising funds and promoting awareness of cerebrospinal fluid leaks

REGISTRATION: at 9.30am

START: Black Isle Showground, Mannsfield Showground Ross Shire, IV6 7RS

LUNCH: Community Cafe in Contin (participants to pay for lunch)

END: Black Isle Showground

FOR FURTHER INFORMATION CONTACT:
Neil MacDonald 07712387301

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

The CSF Leak Association is a Scottish Charitable Incorporated Organisation.
Charity No. SC046319

On 23rd September, veteran rally organiser, Neil MacDonald of Strathpeffer, rallied local tractor enthusiasts to join him for this event, in aid of the CSF Leak Association.

24 tractors took part in total, raising a grand total of nearly £940!

Neil is David and Cerian's neighbour, and has followed David's journey closely over the last four years. He is keen to help raise awareness of CSF leaks, and to support the work we do.

We would like to express our gratitude to all of the tractor drivers that took part in this event, and of course to Neil and his wife.

Left: Neil (seated) with David and Cerian. Photo credit to Ian Rhind.

February 2017 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.

This edition of Leaker Life brings the third and final Q and A summary, with Dr Wouter Schievink. Once again we wish to express our sincere gratitude to The Spinal CSF Leak Foundation for organising the sessions and for allowing is to feature this summary in our newsletter. In addition, we also wish to express our thanks to Becky 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

spinal csf leak
FOUNDATION

Dr Wouter Schievink

Neurosurgeon, Cedars Sinai, Los Angeles

1. IS IT POSSIBLE TO HAVE NERVE DAMAGE AFTER PROLONGED LEAKING?

- Leaks can cause problems with nerves.
- One can get leaks from nerves stretching ie. from arms moving but this is very unusual. A leak can cause problems if leaking for years / decades.
- Often once patients are successfully treated any problems are reversible.

2. WHAT ARE THE COMMON MISCONCEPTIONS WITH SPONTANEOUS INTRACRANIAL HYPOTENSION?

- Many patients may be treated with 2 patches and get better - they then forget

about it. (Like those who come through ER).
- But Dr Schievink treats many patients that have had lots of other scans and treatments and are still struggling to get well. Cases can be complex.

3. MIGRAINES VS LEAKS

- Brain and Spine MRI results - many have normal results.
- Lots of uncertainties because people can be leaking with no evidence on imaging, and only symptoms to go on.

4. CAN YOU DO MORE DAMAGE IF YOU PUSH THROUGH SYMPTOMS AND STAY UPRIGHT TOO MUCH?

- Don't push through activities that make symptoms significantly worse.
- Even if symptoms go on to years or decades symptoms can be fully reversal after successful treatment.

5. MULTIPLE LEAKS

- They are not commonly seen.
- Often a patient will be leaking in one place and then fluid moves around the epidural space. This can look like multiple leaks but it is rare for there to actually be more than one leak at a time.

6. SIH & CONNECTIVE TISSUE DISORDERS

- Some patients do not have a leak, but instead have an elasticity of the dura means it stretches and sags giving similar symptoms as a leak. An EBP can still help this due to scarring.

7. WHAT IS STANDARD AFTERCARE?

- Little evidence base
- There have been no randomised trials regarding treatment or following treatment.
- Ideally after an EBP - 1 month period no exertion, lift no more than 10-15 lb, don't strain on the toilet, avoid soft sand or snow. Etc
- Some others at hospital and other places say avoid 2-3 months.

8. CAN POSITIONAL HEADACHE CHANGE AFTER LEAKING FOR A WHILE?

- Yes positional aspect can get lost
- Perhaps body compensates and pressure is normalised even though leaking.

9. WHAT IS THE NEXT RECOMMENDED IMAGING IF CT MYLEOGRAM DOESN'T SHOW LEAK?

- Digital Subtraction Myleogram under general anaesthesia
- This studies the dye as it is injected into dura. This is good for rapid leaks - pinpoints location well.
- Good for venous fistula leaks

10. DOES DR SCHIEVINK PATCH PATIENTS WITH NO EVIDENCE OF A LEAK ON IMAGING?

- Yes at Cedars Sinai they will try up to 2 split level EBP as a diagnostic procedure. If the patient responds well, will treat further.

11. CAN YOU LEAK OVER 3 WEEKS, HEAL SPONTANEOUSLY THEN REBOUND INTO HIGH PRESSURE?

- Yes, patient stories/ reports point to this

12. RHP vs SIH (Rebound Hypertension vs Spontaneous Intracranial Hypotension)

- Rebound Hypertension usually presents with opposite symptoms
- Same type of problem but symptoms not always as obvious
- In 1994 Dr Schievink had his first patient with RHP following surgery for a cyst which had been leaking for 7 years. 6 weeks later the patient experienced a haemorrhage behind the eye. Then he experienced a headache for 6 weeks and couldn't sleep - needed pillows stacked etc.

13. HOW MANY PEOPLE REPAIRED GO ON TO EXPERIENCE A RECURRING LEAK?

- Dr Schievink used to think this figure was 10% over 10 years. But the more they look into this it seems many of those never felt fully normal after treatment. So they think it is mostly the same leak as before not actually a new one.

14. DOES DRIPPING FLUID FROM NOSE AND EYE INDICATE A SKULL LEAK?

- Skull base leak - fluid runs out of ears, nose or down throats but do not have SIH so HA is not positional.
- Spinal leakers can have a reaction in the lining of the nose so more discharge than normal but this is not spinal fluid.
- Sometimes it is possible to have both skull and spinal leak.

15. CAN YOU HAVE A SUBSTANTIAL LEAK WITH MINIMAL SYMPTOMS?

- Yes. Especially if the leak is long term and the body compensates by making more fluid. Also a a membrane can form around the leak that can improve symptoms.

16. EDS/ CONNECTIVE TISSUE DISORDERS

- The vast majority of patients with SIH have an underlying connective tissue disorder.
- There are many different types of connective tissue disorder.
- Many patients present as tall, slim and lanky.
- Dura is often more delicate. Cysts are also more common.
- Calcium/ bone rubbing against dura or sticking into dura can cause leak from trauma or over time but dura must be weak for this to happen. Many people have spinal degeneration but no leak so has to be an underlying weakness.

17. YOUNGEST LEAKER

- Started symptoms around 2nd birthday

- Came for treatment at age 4/5

18. PERIANAL CYSTS - SHOULD YOU PATCH OR DO SURGERY?

- This depends on the person. Some don't want surgery so they patch up to dozens of times
- Some go straight to surgery with no patch for permanent fix.
- He would personally try blood patches and glue himself before surgery.

19. HOW LONG AFTER EBP WILL YOU KNOW IF YOU ARE FULLY SEALED?

- 3 months important milestone - most know if fully successful by then.
- Few recurrences between 3 months - 1 year.
- Most ongoing problems due to leak not being fully sealed.

20. WHAT IS THE OUTLOOK FOR PEOPLE WITH MANY DIFFERENT CAUSES OF LEAK?

- If bone spur tear surgery cure rate is very high - 95% plus.
- But some do continue with symptoms and they do not know why.

21. CAN YOU LEAK INTERMITTENTLY - SOME DAYS ARE BETTER, SOME DAYS ARE WORSE?

- Yes or the brain is keeping up with a continuous leak.

22. WHAT IS ON THE HORIZON FOR PATIENTS NOT HEALED WITH PATCHING OR SURGERY?

- There is little basic science about the dura and genetics about dura.
- Looking at gene research about dura weakness.
- Animal model experiments on dura to see if they can strengthen the dura is a possible area of research.

23. DOES THE PRESENCE OF LEAKING CYSTS MEAN MORE NORMAL BRAIN IMAGING?

- Cysts hardly ever enlarge after adolescence
- No relationship between type of leak and abnormal vs normal brain imaging
- If cysts smaller than 8mm they are a common finding they do not mean you have a leak but could be connected.

24. IF EBP IS SUCCESSFUL DOES DURA FULLY HEAL?

- Yes

25. IS ICP MONITORING USEFUL FOR SIH?

- Leak symptoms are often due to low volume of spinal fluid rather than low pressure so reading is often normal.

- There is risk with ICP monitoring so they never use it for SIH

26. CAN A CHRONIC LEAKER HAVE SYMPTOMS ONCE A LEAK HEALED?

- There is little data on this
- Often nothing on imaging but probably still leaking.
- Can be difficult to fix.

27. VENOUS FISTULA TYPES

1. Direct vein connection to dura. Blue in appearance but if cut 90% spinal fluid.
2. Tangle of blood vessels where nerve comes out.

28. PRP PATCHING

- No randomised trial to compare blood to PRP
- Some do better with blood some better PRP
- Only do this if am EBP has already failed

29. HOW LONG AFTER BEING SEALED WOULD YOU RECOMMEND WORKING OUT?

- 1 month then resume activity but build up slowly according to symptoms. Do not push yourself.

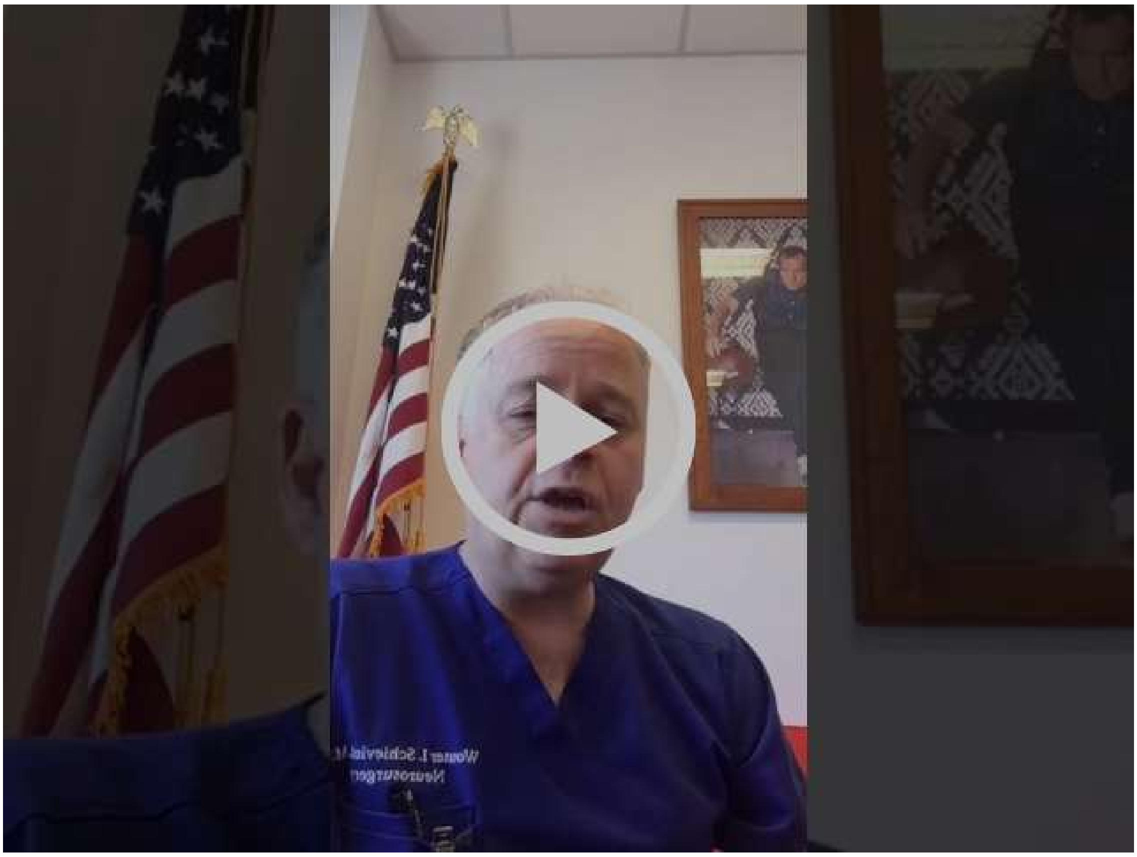
30. DO SPONTANEOUS LEAKS INCREASE THE RISK OF SUBDURAL HEMATOMA?

- This is very common - many more cases than due to needle leak
- Many do not need surgery
- 1 in 3 or 4 occurrence.

31. WHAT IS THE TYPICAL AMOUNT OF BLOOD USED IN AN EBP?

- Once needles placed in epidural space, an infusion of blood will take place and will continue until the patient cannot tolerate the pressure or pain.
- At Cedars Sinai between 3ml to 135ml blood per patch has been used.

You can view the Q and A session via the link below.



This concludes our three part Leak Week 2017 Q & A Summary. Thank you once again to all that took part to make these hugely informative sessions possible.
We look forward to Leak Week 2018!

Psst... Christmas is coming!

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csf leak
association

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