



## Message from the Trustees

Hello, <<First Name>>.

Welcome to the Autumn edition of Leaker Life.

The Association has been incredibly busy over recent months, with farewells to longstanding members of the Board of Trustees, and warm welcomes to new trustees and volunteers.

We have been very focussed on the organisation and delivery of the first ever UK Doctors Cerebrospinal Fluid Leak Study Day. You can read a summary of the day below, which was held on 20th September at the National Hospital of Neurology and Neurosurgery in Central London. We hope this will be the first of many similar days in which leakers and medics come together to share knowledge, expertise and experience in a bid to improve pathways for CSF leakers across the UK.

As we hurtle rapidly towards Christmas, please don't forget to pay our shop a visit, or consider making, or requesting a donation to the charity in lieu of a present.

Finally, from a personal point of view, as I prepare



to step back from the position of Volunteer Newsletter Editor, I wish to say a heartfelt thank you to the readers of Leaker Life, to the Board of Trustees and the members of the Medical Advisory Committee (MAC) for your support, your commitment to the Association, for your brilliantly written features, creative suggestions for newsletter content, and of course for your patience as I pester you for articles!



*Polly Walker*

*Volunteer Newsletter Editor*



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### **A Message from the Outgoing Chairman**

The CSF Leak Association is now into its fourth year as a registered charity and almost six years have passed since I and a small group of CSF leak sufferers from across the globe came together to establish its forerunner, the 'csfleak.info' website.

I could never have imagined back then just how much things would grow and develop, nor indeed the pace of that change. Like those that have gone before, 2019 has been another very active and in many respects ground-breaking year for our charity, its trustees and volunteers. I am honoured to have worked alongside such an enthusiastic and able group of people.

Our resources remain relatively modest, but our ambitions are big and bold. Much of our work is still carried out by our dedicated supporters and, for the most part, is commendably undertaken alongside the many challenges associated with living 'life with a leak'.

Progress can feel frustrating slow at times, but a sustainable, far-reaching and multidisciplinary transformation in health care cannot occur overnight and I believe that it is important to pause occasionally to remember what has already been achieved; we can be proud of the fact that we have already made very significant inroads in a number of priority areas and things are already much better now than they were before.

To that end, I hope that this report will provide an insight into the range of work that has been undertaken from April 2018 to March 2019 (as well as the months between then and the AGM), as we look forward to the year ahead with great optimism for continued progress and advancement in the field of cerebrospinal fluid leaks.

Things are moving apace with some exciting and hugely important milestones on the horizon, but none of this could happen, and the Board of Trustees could not do what we do, without the fantastic support of our membership, our volunteers and our supporters more generally. Thank you to all who've donated their time, their money and their expertise to help make life with a CSF leak a little easier for us all.

Before I draw this introduction to a close, it is with very mixed emotions that I must also announce that I will be stepping down as chair of the CSF Leak Association at the AGM in August. It has been an absolute privilege to help establish and steer this organisation in its early years and I have met some truly amazing, inspirational people and made friends for life on this journey, but the time has now come for me to pass the baton onto someone else.

As I write this piece, who that will be remains unclear, however, and that brings me on to my final few thoughts: charities like the CSF Leak Association cannot exist on goodwill alone. They, we, rely heavily on people being proactive, getting involved and donating their time and energies.

If we are to achieve all that we have set out to achieve and build upon the firm foundations that our small but dedicated group of volunteers have laid, it cannot be stressed enough how vital it is that in the months and years ahead, more people get involved in the work of our organisation.

I very much hope that if you are reading this and you are not already a volunteer, you'll give volunteering with us active consideration. We understand health-related limitations and competing priorities only too well, so we're always happy to work with you to find a task that fits with what you are able to offer. Please reach out to us, if you can.

If you are already involved or have been in the past, please know that we couldn't have arrived where we are without you and you have played an important role; many thanks to each and every one of you, or as they say up here in the Highlands, taing mhòr dhuibh uile!

Best wishes for all that lies ahead.

**David Baldwin**

*Outgoing Chair of the Board of Trustees*

[This article was first published in the charity's annual report in August 2019. Susan Iacovou has since taken over as acting chair, but we are still searching for a permanent solution for both the chairperson and secretary roles. We would encourage anyone who may be interested in either role, or helping with any other aspect of our work and objectives, to get in touch with us at [volunteer@csfleak.info](mailto:volunteer@csfleak.info)]



David Baldwin  
CSF Leak Association Chairman  
2015 - 2019

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**A further message from Dr. Susan Iacovou:**

*At our Annual General Meeting in August the CSF Leak Association Chair, David Baldwin, stepped down and I became Acting Chair. I accepted the role with a huge amount of trepidation, knowing that David would be an impossible act to follow.*

*In 2014, David laid the foundation stones for the CSF Leak Association (with the unwavering support and energy of his wife Cerian) when he launched a*

website sharing the information he had learnt about leaks during his own quest for treatment. He has been the engine driving the organisation forward ever since.

In 2015 David mustered fellow leakers to join him in setting up the CSFLA Charity (awarded charitable status in February 2016), with the aim of ensuring leakers in the UK had access to world class diagnostic and treatment options. Since then, he has worked tirelessly (most of the time from his bed) to promote the Charity's aims and objectives.

In 2016 David's interview with the BBC became the second most read news article on their website (beaten to the top spot by Donald Trump's election) as he sought to raise awareness of the disabling impact of CSF leaks. You can still read David's article by clicking [here](#).

In January 2018 the first ever get together of UK doctors with an interest in CSF leaks took place and this became the Medical Advisory Committee (or MAC). And despite continuing to suffer from serious ill health caused by his CSF leaks and low pressure, in March 2018 David pulled out all the stops to ensure the success of the UK's first Leak Week Campaign.

David's official title for the last few years may have been that of Chair but in effect he has had a hand in website management, administration, public relations, IT management, personnel management, media relations, and so much more. He has taken the Association from website to fully fledged Charity and has certainly earned the rest that we hope will come from stepping down as Chair to concentrate on the planned rebuild of our website.

I know that very many leakers in this country and abroad have benefited from David's work via the website, as a result of the raised awareness amongst doctors in the UK or through the personal support and advice he so kindly offers directly and via our social media pages. David has achieved so much as Chair that it is difficult to do justice to the impact he has had on leakers and on the awareness of leaks amongst both the general public and the medical profession.

David, I'm sure you will agree, is one of a kind. He is also a proud Scot and therefore I'm sure he will appreciate me raising this traditional toast to him (with slightly altered wording - apologies to Robert Burns!):

'Here's to you. Wha's like you? Damn few, and they're a'deid'.

THANK YOU David, from us all - the Board of Trustees, the association volunteers, the MAC, and of course, the leakers, and their family and friends.

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The CSF Leak Association Board would also like to acknowledge and thank Clare Sargeant for all the work that she did for the Charity as a Trustee/Secretary during 2018-19 and before that as a volunteer. CSF leak sufferers across the UK benefited from her support, enthusiasm and commitment to securing change. We are delighted that Clare is continuing to work with us as a volunteer, contributing her skills and knowledge on projects that we are sure will have a positive impact on our members and the wider leaker community.

We are also sorry to see our Treasurer, Pete Marnick, step down from the Board and would like to thank him for his work with the Charity and for the positive contributions that he has made.



Finally, the Board would like to give a huge shout out to Polly Walker who is taking a step back from her editing role on this wonderful newsletter after 3 years. She will be handing over the reins to a fellow volunteer - see our next issue for more about our new editor. Polly has made a big contribution to the work of the Charity and her newsletters have received consistently positive feedback from our members and she will be greatly missed.

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We are delighted to welcome Russell Secker on board as a newly recruited, and much appreciated charity volunteer. His interest in supporting the association originates from his own leaker experience....

*Until my mid-fifties, I was strong, fit and healthy. I had run nearly 200 marathons, and in 2009 competed in the Trans Europe Footrace - nine weeks spent running 3,000 miles from the south of Italy to the north of Norway.*





*But then things started very slowly - almost imperceptibly - to go wrong with my health. Three times I passed out after a hard run. Each of the three episodes was a little different, but what they had in common was a very disoriented, ashen-grey, breathless, unwell me lying prostrate at the finish line for a couple of hours.*

*At the time, I couldn't identify the cause of the horrible feelings, but chalked them up to either undertraining or ageing. Either way, I didn't like the feeling one bit. Each time, I spent several hours getting back to normal.*

*Finally I turned to my GP to discuss matters. He was visibly concerned, and sent me for lots of tests. He did not believe this was purely an ageing effect, as my vital signs (pulse, blood pressure, weight, etc.) were very good for someone my age.*

*So we started with blood tests. A little anaemia showed up, but nothing else alarming. Iron pills and Guinness did nothing to change the trajectory.*

*Next, X-rays. A few shadows on the lungs, but nothing serious. Follow-up MRIs showed nothing which would explain my symptoms. My doctor did scare me a little with his thoughts on the possibility of lymphoma - a form of cancer that begins in infection-fighting cells of the immune system - but my blood tests didn't support that theory.*



So we moved on to my heart - was my trusty ticker beginning to give out after 35 years of running? I was sent to cardiologists who carried out standard tests - ECGs, overnight monitors, CT scans, a catheter angiogram, and finally a treadmill stress test. After only nine minutes, I had to ask the medics to turn off the machine and let me rest on a chair. I knew that something was seriously not right, but it just didn't feel like my heart was the problem.

It turns out I was right.

As winter 2018 approached, things went from bad to worse. I was referred to a neurologist, who while not being able to diagnose any specific condition accepted that something serious was going on. By this time, I now know that my family's fear was that I was developing some form of early onset dementia. I was beginning to sleep a great deal - up to 18 hours a day - and I was suffering really bad headaches whenever I got out of bed. On top of that, my motor skills were starting to fade. I was becoming clumsy and unstable, confused and forgetful. But I was not "with it" enough to understand what was happening.

All I knew was that I was being accused of being demented, which I didn't care for one bit. My mother had died of Alzheimer's a year ago after a 12-year nightmare with the disease, and the thought absolutely terrified me. But unfortunately my sense of reason and awareness had been compromised to the point where I was making very little sense.

Things got worse and worse. Finally in November, my wife Claire took our neurologist's advice and took me to the Accident & Emergency department of the local hospital. I was moved quite swiftly to a ward, and given another series of tests. Cancer or brain tumour were concerns of the doctors, but those tests again came back negative. Whew. But I felt terrible, mentally and physically. My memory of the two weeks I spent in that hospital is as fragmentary as shards of broken glass.

During this hospital stay, Claire and our kids spent lots of time surfing the web, searching for diagnoses which matched my symptoms. The internet thus became a tool in their hands which helped to save my life. They alighted upon a condition called Cerebrospinal Fluid (CSF) Leak, which matched my symptoms precisely. They also found a Neurology Professor at Cedars Sinai Hospital in Los Angeles who is the world's leading authority on the subject, having at least 1,100 surgical interventions in cases of CSF Leak to his credit. This was how we came to learn of Dr Schievink, the man who ultimately saved my life.

As I was nearing the end of my first hospital stay, one of the more switched on doctors there met us in my room, and said he thought I may be suffering from a "little known condition called CSF Leak". Claire promptly reached into her bag and pulled out an Internet transcript of a CSF Leak article, underscoring his thoughts exactly. Although he looked slightly crestfallen to have been scooped by a group of amateur "Dr. Googles", we were happy that someone in the NHS system was finally treating my condition seriously and in a way that made logical sense.

The next stop in the journey, after review by my consultant neurologist, was Charing Cross Hospital, which had more advanced radiology and surgery options. I had spent a miserable Christmas with my family, sleeping constantly and becoming less and less aware of my surroundings. Headaches were a

*constant reminder to lie down, which in turn led to more hours of sleep.*

*In January 2019, we arrived at Charing Cross. I had a brain MRI, and this clearly showed that my brain was sagging down into my spine. It was generally agreed that this was caused by a CSF leak - fluid was leaking from somewhere, reducing the pressure in my skull and thus allowing this sagging. The doctors tried two different approaches to remedy this - blood clot patches and caffeine infusions.*

*The anesthesiologist's first attempt at a blood clot patch was unsuccessful. I felt no better. A caffeine infusion was tried. (Caffeine, it is suspected, increases the body's production of cerebrospinal fluid.) It did not appear to make any difference in my case either.*

*A few weeks later, the anesthesiologist reluctantly agreed to try another blood clot patch, and bingo! By injecting into a different part of my spine, the patch relieved the headache symptoms and swung me from depressed and somnolent to happy and manic! I couldn't sleep, couldn't stop talking and felt that I had recovered.*

*But not so fast. Within ten days or so, the old symptoms started to return. More headaches, more instability, more sleep, and more craziness.*

*So, by this point, the doctors knew from MRI imaging that my brain was sagging into my spine due to a CSF leak. Unfortunately, they could not work out why - or where - I was leaking fluid. I was slowly deteriorating. Claire had confiscated my car keys, to prevent me from driving and potentially causing death and destruction on the roads. She also took my passport, so that I could not take a long-planned holiday to Goa. I was confused and angry at this loss of independence, control and fun. Nothing was making sense to me. I was descending into madness.*

*At the next meeting with our consultant, the idea of flying to the US for treatment was discussed. He had given up on the NHS' ability to "fix" me. He suggested Johns Hopkins hospital in Baltimore, but they had a four month wait for treatment. Duke hospital in North Carolina had similar issues. But Claire managed to connect with Cedars Sinai hospital in Los Angeles. Dr. Schievink could see me in two weeks. He had seen my MRI scans from Charing Cross, and was confident that he could cure my brain sag.*

*So Claire booked our flights to LA, and a hotel room within walking distance of the hospital. We were on our way! My daughter came with us on the flight, and our two sons who live in the US met us in LA. It was great to be together as a family, even in my diminished state.*

*Within three days, we had met Dr Schievink, and he explained what he planned to do. I was to be MRI'd again, to confirm the status of the leak. Then, under general anaesthesia, I would receive something called digital subtraction myelography, a very precise scan of my spine to determine the exact site of the leak. Two days later, again under general anaesthesia, they would perform a laminectomy on the vertebrae next to the site of the leak, to allow access to the dura.*

*Even in my confused state, it was clear to me that Dr Schievink knew exactly*

*what he was doing. Only later, weeks after the surgery, did I come to realise that this set of procedures was extremely complex, and not without risk.*



*Within a week of arriving in LA, I found myself lying in a hospital bed recovering from scans, anesthesia and surgery. My back was miserably sore, but I had made it through without any problems. After two nights at Cedars Sinai, under the care of brilliant nurses and doctors, I could feel the fog of dementia starting to lift. My head didn't ache. Things were starting to make sense. I was even able to slowly walk back to our hotel with my family.*

*Dr Schievink let us know that the cause of my CSF leak had been a dural cyst at T8-9 - which I had probably had since birth - and which had been somehow connected to a venous fistula, a rogue vein which was allowing spinal fluid to escape the dura and into the rest of my body. His surgery involved cutting and cauterising off the fistula, and then placing two aneurysm clips on the cyst. He hoped that his handiwork had stopped any further leakage permanently.*

*A week after surgery, a final MRI clearly showed that my brain was floating again, and my cranial nerves, pituitary gland, and all that tricky wiring stuff was getting back to the right size, shape and position. Dr Schievink had successfully cured me - truly saving my life.*

*What does this mean? My "crazy" symptoms have receded. The "brain fog" has cleared. Senses like smell, taste, appetite, and vision are recovering nicely. And I can finally sleep more normally - eight hours instead of fifteen a night. I can walk without stumbling or falling. Headaches and my painkiller intake is a thing of the past. I can swallow without choking. And I can drive a car again!*

*I now spend an hour a day at the gym. I can even jog for 20 minutes on the treadmill. My short-term memory is still not perfect. But to say that I'm a very lucky CSF Leaker would be a massive understatement.*







### **Desert Island Discs - by Sandie Moore**

I have been a fan of Desert Island Discs for a long time, as you can tell so much about a person when you hear their choices, as well as discovering new tracks and artists. My favourite episode is David Nott War Surgeon, who works at the Chelsea and Westminster Hospital and spends his holidays training surgeons in war zones. When David Nott met the Queen, he choked up when speaking about his work, as he was still traumatised from his latest trip. The Queen told him not to worry about talking and to his relief called the corgis in for him to pat instead. You can listen to this episode [here](#).

I have chosen some of my favourite tracks, as well as tracks that helped me to stay positive during the worst days of the leak. You can click on the titles to listen to the tracks. I hope you enjoy them.

#### [BE THE MAN by Rag n Bone Man](#)

I have a leak caused by disc surgery that has been patched up nine times with glue, muscle, fat and blood patches. I have gone from being able to be up for 15 minutes, to being able to be up for six hours. I found that on the way to see the Neurosurgeon for a post-op eight week check, when I knew the patching had failed, it had to be Rag and Bone Man up **full blast** – Clive never daring to suggest we turn it down just a teeny fraction! It always has to be a sad or soulful song for me when I have to face something tough. The Happy Song would just be all wrong at a time like that.

#### [CHEERLEADER by OMI](#)

This song makes me smile and conjures up the feel of the Caribbean. I really enjoy the trumpet part. Many happy memories of singing along with my boys James and Chris in the car to this one.

## [I GET KNOCKED DOWN BUT I GET UP AGAIN](#)

[by Chumbawumba](#)

The ultimate anthem to lift you when you are down, but not quite out. A great sing-along anthem at parties too, arms raised in defiance. Trumpets again in the instrumental at the end. I love a bit of brass and used to play the euphonium in the British Legion band until it got too embarrassing as a teenager.

## [HARDER THAN YOU THINK – Public enemy](#)

This brings back so many happy memories of the 2012 Paralympics and watching the Last Leg late in the evening every night for a humorous round up of events. We went to the Paralympics and couldn't believe the wheelchair basketball, the guys wheelchairs crashing over and then their immense arm strength flipping the chair back up. As a Physio, I couldn't bear to even watch the Murderball (wheelchair rugby) on TV – brutal on the body! I loved hearing all the back stories of the athletes, which Clare Balding rarely even needed to check her notes about when she was chatting with them – amazing woman. I just loved that 2012 bonded us Brits together and made us proud again. So glad that Seb Coe is type A and did such a perfect job in charge! Favourite characters from the games Ellie Simmonds and Nicola Adams..

## [ONE DAY LIKE THIS – Elbow](#)

From the very first note this makes you feel so good. Okay yes, another London 2012 Olympics anthem, this time from the closing ceremony. We had our 30 year Physio reunion two years ago and my flat mate Sue chose this. She is a real triumph-over-adversity character. She became pregnant in our third year of training (she took the Doctor's words 'you have had a ruptured appendix and could be infertile in the future with all that scar tissue' a little too literally). She took her written finals at eight and a half months pregnant, then had the baby and four weeks later took her practical exam. I have a picture in my mind of us preparing for the practical, with Sue sitting with her notes on one arm of the chair, baby in her lap, spag bol on the arm of the other chair. Sue happily revising, eating and dropping pasta on little Sophie. She still seemed to have limitless energy and enthusiasm and even got a merit in her practical. Inspirational.

## [WILLOW - Joan Armatrading](#)

Two of our best friends had this as their wedding song – a very happy day and I love to sing along to it. I have a deep - and Clive says quite terrible - voice, so no high songs for me. I saw Joan Armatrading in concert and this track and Love and Affection generated such emotion. It's funny how crying at music can be so enjoyable isn't it?

## [YOUR SONG - Ellie Goulding](#)

After three years of trying to have a baby, I remember hearing the Elton John version of this on the radio in the car after visiting some friends and their three super lads. I thought if the miracle occurs, this will be my song for them. I have chosen the Ellie Goulding version because Clive loves it and it will remind me of him on my desert island and of course James -now 17 and pushing every

teenage button - and his brother Chris 15 and super chilled. (Sometimes I fear Chris would actually flat-line if they put an ECG on him).

### [OUTLANDER TITLE THEME SKYE BOAT SONG](#)

The Highlander and Outlander series kept me going through several ops and I love this haunting song. We have some great Scottish friends who took us to look at the magical snow-topped Isle of Skye this year for Clive's 60<sup>th</sup>. The song also reminds me of my favourite concert of all time – the Edinburgh Tattoo. The Lone Piper in the mist on the battlements was spine tingling. I always think it must be great to be Scottish.

### [SKYFALL– Adele](#)

Our family love James Bond and Aston Martins and this is our favourite Bond film – we love the Scottish scenes at the end, though very sad to see Judy Dench's M killed off. Clive had an old DB4 in bits for many years that he couldn't afford to get done up. He sold it to help buy our first house....if only he had kept it! Again more trumpets in this one....

### [WE ARE THE CHAMPIONS by Queen](#)

This track Clive used to play to the boys in the car on the way to all their football matches when they were young. I love Queen and this makes me remember Freddie Mercury and many happy Sundays watching the lads play football.

Now the hard part - **which disc would you save from the waves?** I think it has to be Omi and Cheerleader as I am on a sunny desert island and it will conjure memories of the family singing along. **Luxury item** would have to be my pillow. **Book choice** – a learn to draw and paint book with artists materials and paper – I am rubbish at relaxing and love a project. I found the lying down regime after leak repair ops excruciatingly frustrating, and at one point when they were trying to avoid more surgery, I had to lie down for 22 days, only getting up to go to the bathroom. Ultimate test for a fidget, especially as it made no difference at all to the leak.

**Would I do well with the practicalities and solitude of a desert island?** I am pretty practical – as a child my favourite book was 365 things to make. My Mum was not a great fan of craft and having her table glued, so the book used to mysteriously disappear. I would definitely miss people. My friends and family have been amazing over my rehabilitation from the ops – dropping in to make me laugh and bring dinners. Clive is an old-fashioned Welshman and has two basic dishes – beans on toast and toast under beans.

Thank you so much, Sandie for such a super article! If you would like your Desert Island Discs to be included, please write to us at [newsletter@csfleak.info](mailto:newsletter@csfleak.info)

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## **First Ever UK Doctors (Spinal) Cerebrospinal Fluid Leak Study Day**

20<sup>th</sup> September 2019, The National Hospital of Neurology and Neurosurgery, London



This article was kindly submitted by Clare Joy, a Trustee of the CSF Leak Association, who was able to attend the Study Day.

The study day only became a reality because of the work behind the scenes by the charity's Medical Advisory Committee and in particular, its chair, Dr Manjit Matharu. The Board of Trustees would like to express its sincere gratitude to all the speakers and attendees. It was truly a fantastic day for sharing of



current practice in the UK, learning from published literature on practices from further afield, discussing what could be best practice and learning how much we don't know yet. It was humbling realising the mammoth task ahead of us in producing a consensus statement and guidelines. The day was attended by thirty healthcare professionals (neurologists, neurosurgeons, neuroradiologists, anaesthetists, nurses) and five 'expert patients' - trustees Clare Joy and Tamsin Trevarthen and volunteers Russell Secker, Sandie Moore and Dr Jenny Pople.



**CEREBROSPINAL FLUID LEAK STUDY DAY**  
 Wolfson Lecture Theatre, The National Hospital for Neurology and  
 Neurosurgery, Queen Square, London. WC1N 3BG

**PROGRAMME**

FRIDAY 20 SEPTEMBER 2019		SPEAKERS
<b>09.00-09.30 REGISTRATION AND COFFEE</b>		
09.30-09.40	<b>Welcome and Introduction</b>	Manjit Matharu
<b>SESSION 1 OVERVIEW AND DIAGNOSIS</b>		
09.40-10.10	<b>Systematic Review on SIH</b>	Chair: Dr Alok Tyagi Manjit Matharu
10.10-10.30	<b>Orthostatic headache - working through the differential diagnosis</b>	Callum Duncan
10.30-10.45	<b>Are the diagnostic criteria for SIH fit for purpose?</b>	Simon Ellis
<b>10.45-11.15 COFFEE BREAK</b>		
<b>SESSION 2 INVESTIGATIONS</b>		
11.15-11.30	<b>Lumbar puncture: is it a useful investigation?</b>	Chair: Dr Indran Davagnanam Jane Anderson
11.30-12.10	<b>Overview of the Neuroimaging Techniques: which technique and when?</b>	Indran Davagnanam
12.10-12.30	<b>What is the role of ICP monitoring?</b>	Ahmed Toma
<b>12.30-13.15 LUNCH</b>		
<b>SESSION 3 MANAGEMENT</b>		
13.15-13.30	<b>Conservative management and drug treatments</b>	Chair: Dr Ahmed Toma Paul Dorman
13.30-13.45	<b>Epidural blood patches</b>	Anthony Ordman
13.45-14.00	<b>Evidence base for surgery in management of SIH</b>	James Walkden
14.00-14.30	<b>Management pathways at:</b>	
	- Glasgow	Alok Tyagi
	- University Hospital of the North Midlands	Brendan Davies
	- The National Hospital for Neurology and Neurosurgery	Manjit Matharu
14.30-15.00	<b>Discussion</b>	Faculty
<b>15.00-15.30 COFFEE BREAK</b>		
<b>SESSION 4 GUIDELINE DEVELOPMENT</b>		
15.30-16.30	<b>Discussion</b>	Chair: Dr Manjit Matharu Faculty



Above Left: Dr Anthony Ordman. Above Right: Dr Matharu.

### Session 1: Overview & Diagnosis

1. Systematic review on Spontaneous Intracranial Hypotension, Dr Manjit Matharu

Dr Matharu presented the preliminary results of a systemic review of all English language published literature on Spontaneous Intracranial Hypotension (SIH) found using specific key words. He credited Dr Linda D'Antona for doing most of the work involved in identifying studies for inclusion in the review and for aggregating the results across multiple studies to present in this presentation. The review was comprehensive and touched on a multitude of aspects of SIH but from a patient perspective it was telling that there were no studies on the impact on patients' quality of life. Aspects touched on included the type of headache on initial presentation to neurology, pressure measured by lumbar puncture, the findings of brain and spinal imaging, location of leak, outcomes for conservative treatment (bed rest), outcomes for patching and surgery. There was discussion throughout when a result presented did not match the speaker or audience's experience, e.g. high success rates for first blood patch. It is hoped that this work will be published soon and the message is clear, more research with better datasets is required.

2. Orthostatic headache - working through the differential diagnosis, Dr Callum Duncan

Dr Duncan presented some other diagnoses to consider when there is a suspicion of the leak. He said the main differential is Postural orthostatic Tachycardia Syndrome (PoTS) which may present with worsening headache when upright with tachycardia. He explained how the most common differential is chronic migraine – a patient experiencing a migraine will want to lie down but that this is most likely due to motion sensitivity and the patient will feel better lying still and not moving.

3. Are the diagnostic criteria for SIH fit for purpose? Dr Simon Ellis

Dr Simon Ellis outlined the evolution of the diagnostic criteria for SIH from the 2004 International Classification of Headache Disorders 2nd edition (ICHD-2, section 7.2.3) to the ICHD-3 in 2018 and touched on particular papers where authors had proposed changes to the criteria or where published results were of interest, e.g. Schievink 2011 (criteria proposed - click [here](#) to read the associated paper), Kranz 2016 (imaging is not conclusive), [Tanaka](#) 2016 (age and sex differences in presentation - click [here](#) to read the associated paper) and Graf 2018 (can't distinguish between SIH and PoTS; click [here](#) to read the associated paper). Discussion included how problematic the diagnostic criteria are because they make reference to low CSF pressure and positive image findings but we know that normal pressure and normal imaging can be found in a patient with a leak. There is the additional diagnostic hurdle that some patients can have more than one headache type at play.



Above Left: Dr Indran Davagnanam. Above Right: Mr Ahmed Toma.

## Session 2: Investigations

### 4. Lumbar puncture: is it a useful investigation? Dr Jane Anderson

This was quite an interactive presentation where the audience shared their practice on whether or not a lumbar puncture to measure the CSF pressure should be done and if it was normal would that rule out a leak. Many felt that it should not be done as a stand alone test in classic presentations but that it is often used to rule out other conditions/diseases when the diagnosis is not clear. Many also stated that opening pressure should be done at the time of a myelogram (if sending the patient for a myelogram).

### 5. Overview of the Neuroimaging Techniques: which technique and when? Dr Indran Davagnanam

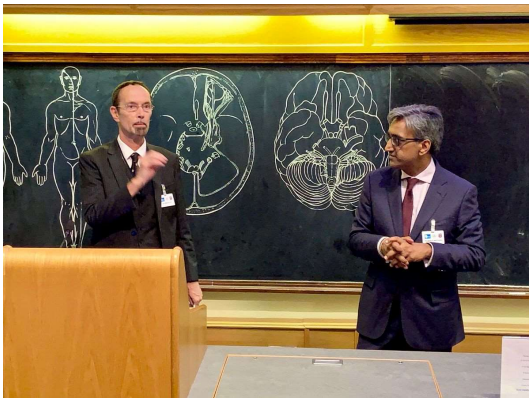
Dr Davagnanam spoke about the different types of imaging that could be used in determining the presence of a leak and for determining the leaks location. He acknowledged that clear imaging does not rule out a leak. Discussion in the Q&A touched on radiologist training in spotting the sometimes subtle signs of a



leak, particular methods for performing dynamic CT myelography, the use of gadolinium contrast in MR imaging and what kind of images the audience would request.

6. What is the role of Intracranial Pressure (ICP) monitoring? Mr Ahmed Toma

Mr Toma described the different technologies for measuring ICP and went on to explain that the work with ICP monitoring in Queen Square pertained to the changes in 'median ICP' and 'pulse amplitude' in patients with hydrocephalus and CSF disorders (click [here](#) to read the associated paper) and how the team there hopes to publish more in the future. So far they've found that roughly one third of patients undergoing ICP monitoring for query CSF leak are found to have low pressure with another third having normal pressure and the final third found to have high pressure.



Above Left: Dr Simon Ellis and Dr. Matharu. Above Right: Mr Jim Walkden.

Session 3: Management

7. Conservative management and drug treatments, Dr Paul Dorman

Dr Dorman explained how conservative management (bed rest) is not routinely prescribed in Newcastle due to the delay in seeing patients meaning that most patients have already tried bed rest. Little is known about how many spontaneous leaks resolve with bed rest compared to iatrogenic leaks, e.g. lumbar punctures. When discussing drug treatments the Cochrane systematic review on post dural puncture headache was discussed (click [here](#) to read the associated paper) where there was some evidence for caffeine, gabapentin, theophylline and hydrocortisone. The discussion amongst the audience was that many centres do not routinely offer caffeine infusions anymore because patients still ended up needing a blood patch.

8. Epidural blood patches, Dr Anthony Ordman

Dr Ordman detailed his procedure for consenting, administering and follow up of blood patches. He expressed his belief that not only is it important to explain the benefits and risks of a patch, as with any medical procedure, but also to explain what to expect, how symptoms may change and when to consider another patch. The audience discussed the theory that the course of symptoms after a patch was bimodal – early relief (sometimes total, may be short lived) followed by a lull and then after a few weeks a more gradual improvement. The underlying mechanism remains a mystery.



## 9. Evidence base for surgery in management of SIH, Mr James Walkden

Mr Walkden treated us to a whirlwind tour of the literature. He touched cranial leaks - patients with anterior fossa leaks (nasal) tend not to have SIH whereas those with middle fossa (ear) do. He stressed that surgery for cranial or spinal leaks depended on good imaging studies for locating the leak site but also to determine the vasculature supplying the nearby nerves to reduce complications. He talked us through some fascinating short videos of surgeries he had recorded while trying to hunt down and seal a defect in the dura.

## 10. Management pathways at:

- Glasgow, Dr Alok Tyagi
- University Hospital of the North Midlands, Dr Simon Ellis
- Newcastle, Dr Paul Dorman
- The National Hospital for Neurology and Neurosurgery, Dr Manjit Matharu

By this time of the day we were well behind the programme due to the amount of worthwhile discussion happening at the end of each presentation. This final presentation was quite brief where each of the speakers shared what the pathway was at their centre. There was some discussion on how rigid or otherwise each centre's pathway was and much discussion on the need for a guideline document. From a patient perspective it became evident to me that all the healthcare professionals in the room agreed on one thing – that multidisciplinary team working was at the core of their service and that any plans for the future would have to work for all disciplines and need their buy in.

## Session 4: Guideline development

Finally we reached the last session with very little time left but as it happened a lot of the questions planned to be raised in this session were discussed throughout the day. The majority of the audience agreed that a guideline or consensus statement was the best way forward with the aim of reducing diagnostic delays and time to intervention (e.g. patching). The exact format and nature of the process and the personnel required are yet to be bottomed out but it soon became clear that funding is our next big hurdle. The process is likely to be long and involve multiple meetings and possibly require pertinent clinical questions (take your pick from above!) to be answered via research before a consensus can be achieved.

In conclusion – a thought provoking and hopeful day made even more so by a fantastic leaker meet up and the engagement of interested healthcare professionals who really do care about our small (but vocal) community. I am both humbled by their compassion and slightly dumbstruck by the sheer size of the task ahead of us especially when it feels like the NHS is working beyond capacity already.



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