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## Message from the Chairman

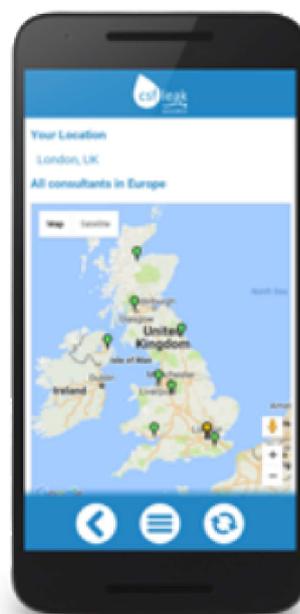
Hello, <<First Name>>.

Hello and welcome to this special Christmas edition of our Leaker Life newsletter.

As we approach the festive season and New Year beckons, it's customary to look back on the year that was and reflect: and wow, what a busy year it's been for both the CSF Leak Association and leaks more generally!

January saw us open up for membership and we're now approaching 150 members with a steady flow of people continuing to join us each month, which is just fantastic. This exceeds what we had expected for year one and helps to strengthen our voice in campaigns and when working with other organisations.

February saw the first ever #LeakWeek awareness campaign on social media, with activity here in the UK, the USA and in other countries around the globe. This event is certain to go from strength-to-strength each year, so please look out for announcements in the near future and get involved in the push to raise awareness far and wide.



An Android App for CSF Leakers is available! It's absolutely free and available to [download from the Google Play store](#).

The app provides easy access to key information and resources about CSF leaks, all at the click of a button or tap on a screen!

You can access information about

At Easter, we held our first full AGM and elected a new Board of Trustees. Some familiar faces were re-elected and we also welcomed on board a new trustee. As the year has progressed, while external commitments have led to two further trustees stepping down, we have been joined by another fresh face and are soon to be joined by one or two more in early 2018.

The organisation cannot operate without trustees and volunteers, so I would encourage anyone who has an interest in CSF leaks and shares our aims to reach out to us and see how they can get involved; if trusteeship isn't for you, we're always looking for volunteers to help with particular tasks or initiatives, so please do drop us a line and get involved with the charity.

In the autumn, the world's first Spontaneous Intracranial Hypotension Symposium was held in California, organised by the Spinal CSF Leak Foundation and Cedars-Sinai Medical Centre. The event was very well attended, with people travelling from around the globe, and the speakers presented a range of fascinating talks about spinal CSF leaks and a wide range of related issues. If you've not yet watched the webinar series from the event, you can do so by clicking [here for the patient track](#) and [here for the professional track](#).

Perhaps the most important achievement of 2017 for the charity has been the ground work carried out for our Medical Advisory Committee. We now have a group of top doctors from around the UK signed up and are delighted to announce that the first meeting will be held in London at the end of January 2018. We believe passionately that this committee will provide a key vehicle for raising awareness and driving change within the NHS, and we very much look forward to updating you all on progress from the meeting in the next edition of Leaker Life.

cranial and spinal CSF leaks, and view a list of must-read medical journal articles, all off-line; ideal for use during an appointment with your doctor or when explaining things to friends and family.

View our global map of CSF leakers and add/edit a pin for yourself, search for doctors with some CSF leak experience near you (aimed at EU residents), or bring up a copy of our medical accommodations cards whenever you need it.

The app is updated periodically with new content, so please make sure that you select its 'auto update content' setting. If you have any ideas or suggestions for the app, please drop us a line.

To get a copy of the app, search for 'CSF Leak' in the Google Play app store, or point your device's browser to: [www.tinyurl.com/csfl eakapp](http://www.tinyurl.com/csfl eakapp)

All that remains to be said is Merry Christmas and a Happy New Year.

Best wishes,

David Baldwin  
Chairman

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We're thrilled to announce that you can now set up fundraisers for the CSF Leak Association via Facebook.

It's simple and easy to do, with only a few clicks of the mouse or taps on your mobile device.

Facebook currently charges no fees for this service, so every penny that you raise goes direct to the CSF Leak Association.

Find us at [www.facebook.com/csfleakassociation](http://www.facebook.com/csfleakassociation)



**#leakweek**

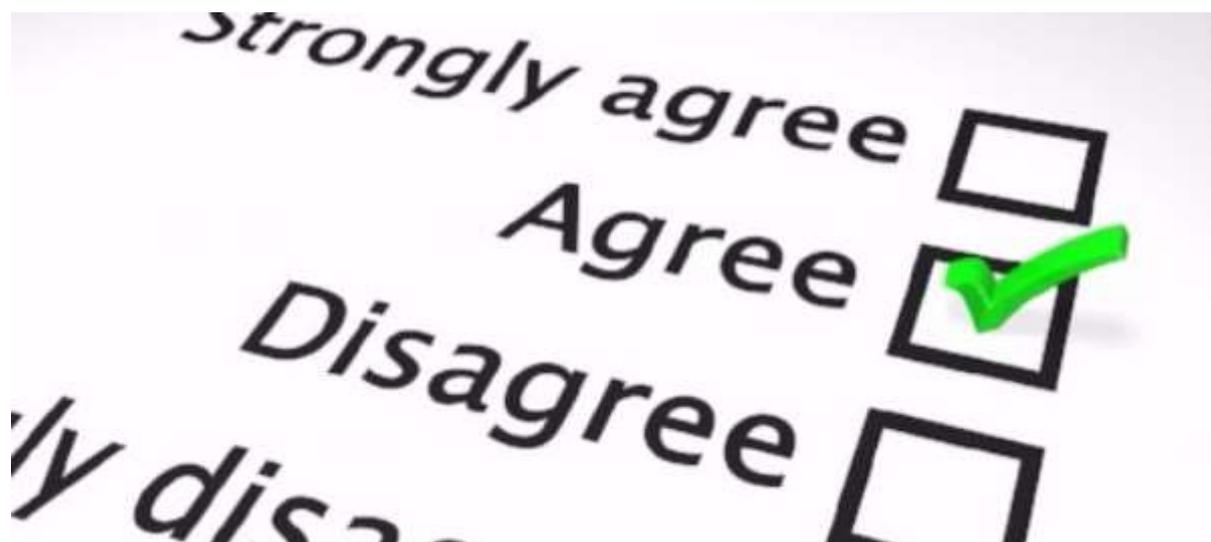
*Leak Week 2018 will run from 26th February - 4th March.*

Throughout the week a variety of activities and events will enable us to work together to raise the profile of CSF Leaks, and of course, to engage in some fundraising too! Why not get planning? Here are some fundraising ideas to get you started...

1. A sponsored event: shave your head, give something up, something sporty.
2. Have a party or a feast! Afternoon tea, a picnic, Cèilidh / Céilí, a disco, dinner party, coffee morning, barn dance, garden party, comedy night, karaoke, a fashion show, an oscar night, a fancy dress party, a quiz night or bingo!
3. Have a sale! An art exhibition, a cake sale, jumble sale, a raffle, tombola, unwanted items, bring and by, clothes swap, things you've made.
4. Community events - would your local school / church / businesses or shops support us? By having a dress down day or dress with a theme day, a sponsored event or by having a collection?
5. Get active: an extreme sporting event such as abseiling, parachuting, climb a mountain, etc. A sports day or whacky races, mini olympics, or team games tournament.

Don't forget! Let us know what you're up to so that we can support you by spreading the word and featuring an article on your event in the newsletter. And always contact your local press too!

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## THANK YOU

For taking part in our recent survey. The survey received a fabulous response, with 51 completed, producing a number of interesting and innovative suggestions for how the association might further our work.

- Many of you said that you would like to hear more personal and positive stories from leakers, or recovered leakers. At present, most of our newsletters include a 'Spotlight on a Leaker' and whilst we try and include both cranial and spinal leakers as well as recovered and ongoing leakers, we are always keen to hear from volunteers happy to share their stories. Please do drop us a line at [newsletter@csfleak.info](mailto:newsletter@csfleak.info) if you would be happy to share your story.

- Several of you requested a tool in which to link up with other leakers in your area. Have a look at our interactive map by clicking [here](#). If you would like to feature on the map, please drop us a line at: [office@csfleak.info](mailto:office@csfleak.info) or download our android app and add a pin from there. Unfortunately, we aren't able to identify Facebook users according to their region so the map helps to plot leakers around the country and globe! Sharing information such as this is at the individual user's discretion, but will always be processed in accordance with UK data protection laws.

## Interactive Global Map of CSF Leaks

Our interactive map of CSF leaks plots the location of CSF leak sufferers across the globe. It is intended for general interest and information, as well as aiding in the examination of any potential correlation between CSF leaks and location. Our thanks go to Bob Paddock for his help establishing the map.

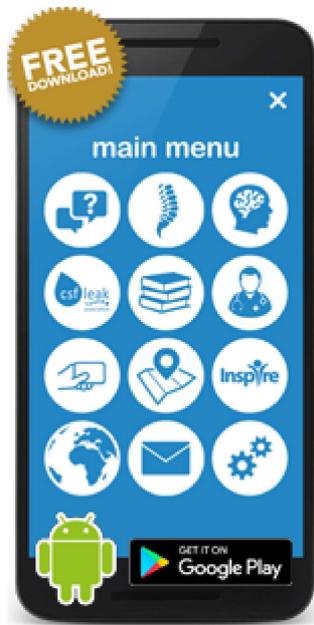


**Map Hint:** Map pins show the location of a CSF leak sufferer. Click on a pin for more information.

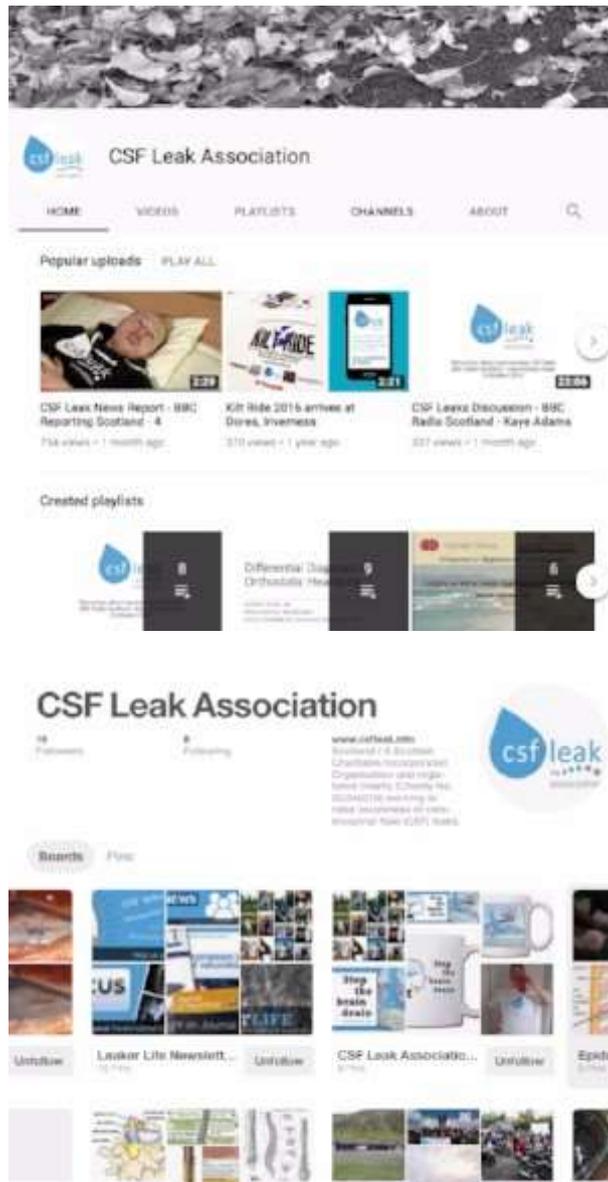
**Map Legend:** ● Spinal Leaker ● Cranial Leaker ● Spinal & Cranial Leaker ● Leak Location Unknown

**Total map pins:** 275 (Spinal: 195, Cranial: 47, Spinal & Cranial: 11, Unknown: 21)

- Please also let us know your experiences of consultants – we are always keen to add medical professionals to our search tool and rely on you, our leaker community, to share this information with us.
- You have asked for fundraising ideas and links... please see above! If you decide to fundraise, please let us know so that we can share your event and fundraising page.
- Many of you didn't know that you could download a CSF Leak Association Android App. Check it out in the Android App Store!



- We also have a Pinterest page, and a YouTube channel. Click the logos below to find our pages. We will be joining Instagram shortly, so keep an eye out for us over there too.





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

Cerian Baldwin, a Trustee of the CSF Leak Association, was able to attend the symposium. Here she reports on her experience of the day:

The Spinal CSF Leak Foundation's CSF Leak Symposium in October 2017 was a world first on many fronts. Never before had the world seen a gathering of doctors with an interest in CSF leaks. Never before had there been a formal gathering of CSF leakers and never before had CSF leakers and doctors been side by side at the same event.

As someone who is fit and well and able to travel with a strong interest in CSF leaks it was an event I couldn't miss. As a trustee of the only other charity in the world for CSF leaks, the CSF Leak Association, I also wanted to show our support for the work of the USA's Spinal CSF Leak Foundation.

I was nervous on two fronts – one, I hate flying and two, meeting all these people who I sort of know in the leaker world (via Facebook). Getting the 11+ hours of flying out of the way turned out to be not too bad and as for meeting all these people... easy. Our 'Leaker' family is a very warm one no matter where you come from or who you are. I put many names to faces and also got to see some old faces too. It really was like a family reunion.

The day was split into two tracks – the Patient/Caregiver Track and the Doctor's Track. Each had their own room with a plenary session in the afternoon for both groups to come together. Everyone mingled over coffee and lunch and many ideas were shared.

I attended sessions in both tracks as some were more American focused and given the distance I had come I wanted to get the most out of my time. The sessions were far ranging from self-care for patients to new techniques and advancements for doctors. All of these are now available to view [here](#) so have a look for yourself and see what you think.

The highlights for me were hearing about the new diagnostic and treatment techniques being tried. This gave me renewed hope. Seeing doctors sharing ideas and thoughts was inspiring. You could see new ideas developing there and then. I do believe that with more joint collaboration that diagnosis and treatment will become better and more mainstream across hospitals worldwide.

I was really touched to meet fellow CSF Leak 'carers'. Whilst I've been honoured in the past to meet CSF leakers, I've never had the opportunity to talk to fellow carers about the unique challenges of caring for someone with a CSF leak. It really was like listening to myself talk and made me realise I'm not alone.

This was the key message for the day, and one I hope that those who couldn't make it can take away; CSF Leakers and those who treat and care for them are not alone. There really is a leaker family out there. Whilst it is hard to travel and meet face to face, there are a good many doctors and other carers working to try and improve the future outcomes for CSF leakers. I hope that our wider leaker family can take strength for that.

If you would like to see what happened on the day for yourself or hear what the doctors had to say then tune into for videos of each session by clicking [here](#).

The planning for the next Spinal CSF Leak Symposium is already underway. This will take place on the 13-14 of October 2018 in Los Angeles.



**Connie Deline, MD**, Course Director  
Intracranial Hypotension Patient  
Co-founder and VP, Spinal CSF Leak Foundation  
Camp Hill, PA



**Peter G Kranz, MD**, Associate Professor of Radiology, Department of Neuroradiology  
Duke University, Durham, NC



We're looking for volunteers to help with our work. Our organisation is entirely run by volunteers and we cannot achieve our aims and objective without the support of others.

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 a 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](mailto:volunteer@csfleak.info)

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**Update on our Medical Advisory Committee**

The 20<sup>th</sup> January 2018 will mark the inaugural meeting of our Medical Advisory Committee (MAC), where a number of medical professionals with an invested interest in CSF Leaks will come together at a venue in Central London, with a view to establishing the roles and responsibilities of the MAC, the ongoing plan of work, the annual objectives, and other business, such as the appointment of the chair and secretary.

We are delighted to formally announce the inaugural clinical members of the MAC –

- 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 Brendan Davies, Consultant Neurologist, Royal Stoke University Hospital, UHNM NT
- Dr Simon Ellis, Consultant Neurologist, Royal Stoke University Hospital, UHNM NT
- Dr David Butteriss, Consultant Neuroradiologist, The Newcastle Upon Tyne Hospitals NFT, Royal Free Infirmary

The CSF Leak Association firmly and wholeheartedly looks forward to working closely with the MAC in the years to come.



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

[www.csfleak.info/shop](http://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.



*Psst... Christmas is coming!*



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Look out for the Spring Newsletter towards the end of March 2018, with additional news and updates released via social media or in the form of a special edition newsletter, directly to your inbox.

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## Spread the word!

If you enjoyed this newsletter, why not share it on social media or email it to your friends?

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 Forward this newsletter to a friend

 Pin this newsletter to your board

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The CSF Leak Association is a member of the [Scottish Council for Voluntary Organisations](#).

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