



**CSF LEAK
ASSOCIATION
ANNUAL
REPORT
2024-5**

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IT'S BEEN QUITE A YEAR



Read on to find out how we've made a difference for people living with CSF leaks.

WE'RE FIGHTING FOR SWIFT ACCURATE DIAGNOSIS EFFECTIVE TREATMENT AND PREVENTION OF ALL CSF LEAKS



We're bringing people together to break down the barriers that prevent those living with CSF leaks accessing treatments, and working to support research breakthroughs.

How we're getting there

→ We are listening to and working with people living with CSF leaks, healthcare professionals, researchers and many others to drive change.

→ We're championing the most effective ways to accurately diagnosis and treat CSF leaks to get people back on their feet living normal fulfilling lives

→ We are building a strong, collaborative community to drive the development of multidisciplinary teams essential for the accurate diagnosis and effective treatment of CSF leaks

A YEAR OF HOPE AND PROGRESS

A year on from publishing our groundbreaking world's first clinical guideline for management of CSF leaks - individuals living with CSF Leaks still experience enormous challenges. But, working together, we have created momentum and achieved change.

In 2024 we were confronted by the stark reality of the inequality of healthcare provision for people with CSF leaks. Lack of awareness of CSF leaks and frequent misdiagnosis led to inappropriate care being delivered to the majority of patients.

A fortunate few live in select areas with knowledgeable specialists or are able to afford to travel to private consultations with specialists. We hear from people with CSF leak symptoms living with the worry that their symptoms are not taken seriously, unable to continue working while the cost of living crisis is making the condition harder to cope with. Those who struggle to make ends meet in normal times are feeling the brunt of this even more, and inequalities in health are growing wider.

The CSF Leak Association continues to work to address this situation: adding our voice to campaigns to tackle health inequality for rare conditions and neurological disorders, learning what information and support you need from us right now and working tirelessly to provide it. The specialist counseling service funded by the National Lottery Scotland has been a lifeline for individuals struggling to cope with the life changing restrictions and suffering a CSF leak imposes. There was a call to make the guideline more accessible to patients in an easy to understand format. We listened and with the support of Costello Medical who specialise in medical communication we produced an infographic for patients and another for clinicians to make the guideline easily accessible to all.



In 2024 as we marked the first anniversary of the guideline, it remains the only clinical guide for management of spontaneous spinal CSF leaks in the world, but a landmark new partnership with multidisciplinary specialists across Europe heralds the start of a journey towards a European guideline.

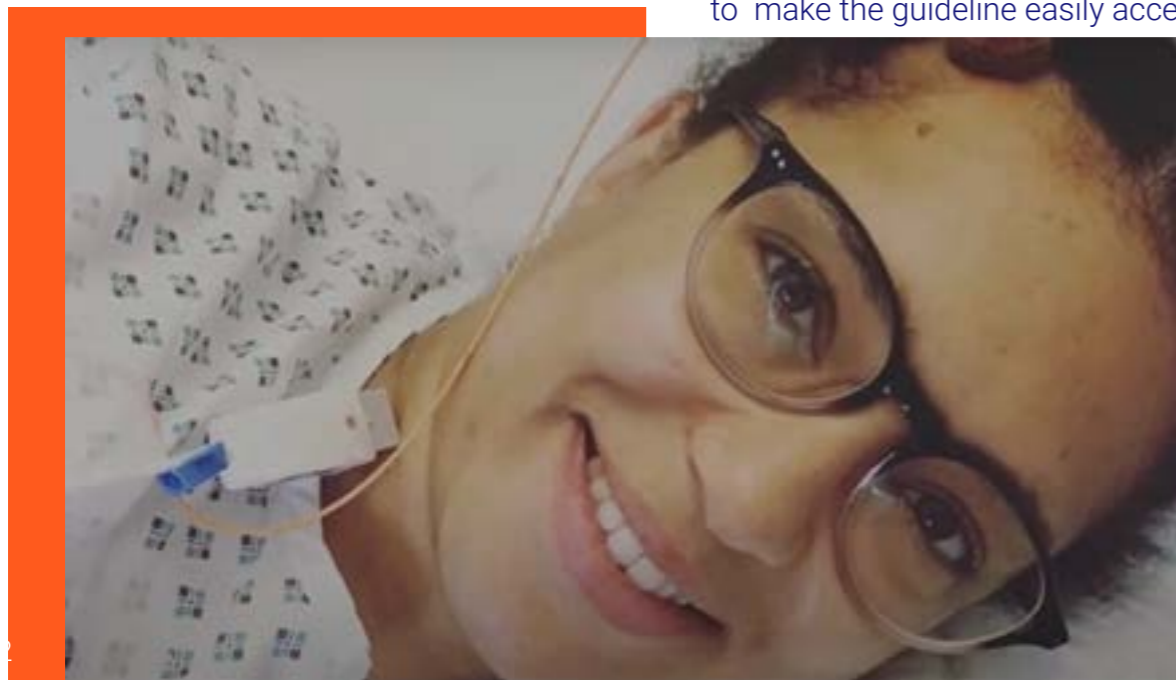
The launch of our UK guideline continues to stimulate global research with the patient voice at its heart and encourages patients, medical, and research communities to come together to make an even bigger impact.

This year more people are being accurately diagnosed and effectively treated for CSF leaks allowing more people to return to work and care for their families. With growing numbers of patients, we've succeeded in pushing the condition up the agenda.

It will be a long and difficult road, but we're going to do everything in our power to help our colleagues in the NHS build the multidisciplinary teams needed to deliver best practice care to CSF leak patients, while scaling up our ambitions to tackle the inequalities.

Through publishing the guideline we facilitated more clinicians to treat CSF leaks in more locations around the UK and beyond. Working together with our partners in the medical community we continue to publicise them, through presentations at medical conferences worldwide, podcast interviews and a series of webinars

In these tough times we're so grateful to our partners and supporters for continuing to stand with the CSF Leak Association in our mission. Your support means we can continue to help everyone trying to manage their condition under such challenging circumstances, while working tirelessly for a future where all individuals with CSF leaks are treated equally, swiftly and effectively to reduce suffering and harm in society.



Clare Joy
Chair



TREAT AND PREVENT CSF LEAKS TO END THE HARM

WHAT WE'RE AIMING TO ACHIEVE

- ✓ More people with CSF leak benefitting from the new guideline, to receive diagnostic scans and treatments that resolve symptoms and prevent harm.
- ✓ More people will be protected from suffering with a CSF leak.
- ✓ More people will get the quality of care they need to manage their CSF leak.
- ✓ Fewer people will get CSF leaks.
- ✓ More people will live healthier lives free of CSF leaks, through equality of access to treatments.

Our strategy is focused on curing and protecting people from CSF leaks, as well as helping people to live well with the condition. We want to end the harm of CSF Leaks within a generation.

- To get us there faster, we're making sure we're...
- 1** Fighting CSF leaks with you.
 - 2** Tackling inequality.
 - 3** Raising awareness.
 - 4** Learning and improving together.

TURNING THE TIDE

Working together to raise awareness of CSF leaks to deliver life changing treatments to sufferers

Pam was one of the many individuals with a CSF leak misdiagnosed each year. Pam was diagnosed with Dementia which reversed after an accurate diagnosis and effective treatment for her CSF leak.



The testimonials on the CSF Leak Association website gave us the information and courage we needed to seek a second and third opinion on Mum's condition, which ultimately saved her life.



Awareness and education matter!

Pam and many others with CSF leaks suffered the harsh reality of the findings from an observational survey put together by the CSF Leak Association - "Few general practitioners or emergency medicine physicians had ever been involved in the care of a patient with Spontaneous Intracranial Hypotension (SIH) or received teaching about SIH. Only 5% general practitioners and 2% emergency medicine physicians were confident in recognising the symptoms of SIH."

For these reasons, and many more, we worked hard to create formal clinical guidelines to educate healthcare providers on best practice healthcare around SIH and spinal CSF leak in order to increase the number of people with CSF leaks being accurately diagnosed and effectively treated; enabling a return to active, pain free, productive lives.

Greater awareness helps shorten delays to correct diagnosis and treatment. More education for health professionals increases familiarity with diagnosis and treatment. And more research is crucial to improving testing and treatments,, key to better understanding incidence and underlying causes.

The Guideline played a vital role in stimulating research and progress this year. Ranked among the top 5% of all research outputs and cited in 63 research papers, it is clearly shaping the future of care. With over 97,000 downloads, clinicians around the world are embracing the Guideline to deliver best practice care – turning knowledge into action and making meaningful improvements for CSF leak patients.

We are a charity run by a small but dedicated group of volunteers most of whom are affected by CSF leaks. Volunteering has been at the core of what we do since the charity was founded in 2016. All of our achievements have only been made possible through volunteers working together, sharing knowledge and expertise for the common purpose, to improve the lives of people with a CSF leak. We are extremely grateful to everyone who has generously given their time, be they medical experts, IT specialists, graphic designers or administrators and more, all are a crucial part of the work we do and we thank everyone of you for your support.

Working closely with patients, international medical experts, other charities and corporate supporters We continued to deliver a number of exciting projects throughout the year,

The annual awareness event Leak Week 2024 saw the culmination of months of work with our sister charities and partners, The Spinal CSF Leak Foundation in the USA and Spinal CSF Leak Canada, giving the event international coverage. Together, we launched a week-long campaign encouraging people to spread awareness of CSF leaks to family friends and healthcare providers; to incite improvement of access to diagnosis, treatment and care for all sufferers from the condition.

We focused particularly on dispelling the myths and misconceptions that hinder an accurate diagnosis for too many patients, having learned from the results of our healthcare professionals survey that few general practitioners or emergency medicine physicians had ever been involved in the care of a patient with SIH or received teaching about SIH. Only 5% of general practitioners and less than 3% of emergency medicine physicians were confident in recognising the symptoms of SIH.



A social media buzz around the posts and stories, along with the combined reach of the three charities on our vibrant social channels, increased world-wide knowledge about this under-diagnosed and disabling neurological disorder and the sharing of information about CSF leaks encouraged more people to seek an accurate diagnosis and timely effective treatment. As always, everyone who contacted us suspecting they may have a CSF leak was signposted to our websites for more information and our find a CSF leak specialist doctor page.

Early diagnosis and treatment can significantly reduce suffering, improve patients' quality of life and help prevent further complications. Awareness is key to timely diagnosis and better outcomes.

Our fundraising event Ride London coincided with leak week, and our riders gave our isolated community a boost to see photos of the cyclists in CSF leak shirts bringing attention to CSF leaks on the ride and pedaling to raise funds on their behalf.

Providing reliable information is vitally important in our educational work. It was a delight at conferences to meet so many professionals interested in our work bringing attention to spinal and cranial CSF leaks, advocating for delivery of accurate diagnosis and effective treatments to patients and increasing knowledge of CSF leaks.

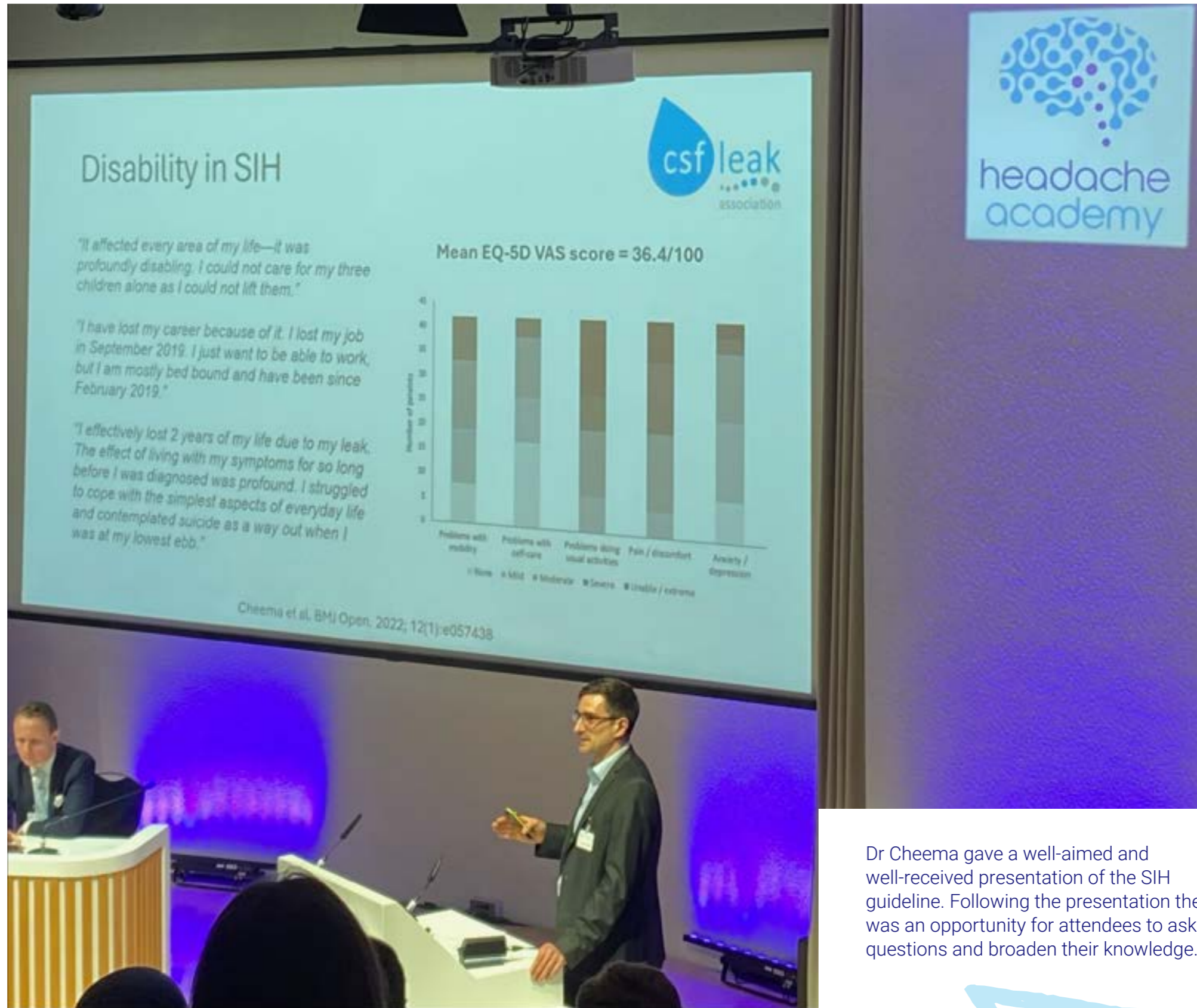
The charity were invited to have a stand, at the Headache Academy event held at the Royal College of Physicians in London. This was a great opportunity to engage with delegates and bring the patient perspective to the fore. The first day was for headache specialist nurses who are so crucial in the care of CSF leak patients. The following two days were aimed at headache specialists and those in general practice and emergency medicine interested in headache disorders. Our patient and healthcare professional surveys identified that these are the specialist who are often where those with a CSF leak will first present. The survey identified lack of awareness and misconceptions about the condition along with a lack of confidence in how to recognise and care for patients.

At a training event in Wales organised by the British Association for the Study of Headache (BASH), once again Dr Cheema gave a presentation on the guideline which is much needed and much appreciated by the faculty and our trustee Bern attended representing the Charity

Prof Matharu the head of our medical advisory committee ventured further afield to present the SIH guideline at the International Hydrocephalus Society conference held this year in Japan. Importantly this event attracts delegates from all the specialist disciplines that need to work together to successfully diagnose and treat CSF leaks most effectively.

Our trustee Bern represented the CSF Leak Association at the biggest headache event in the UK where 300 neurologists, GP's and specialist nurses were in attendance at the biennial International BASH headache conference.

These events are crucial methods of stimulating interest in CSF leaks amongst healthcare providers, focusing attention where it is needed most.

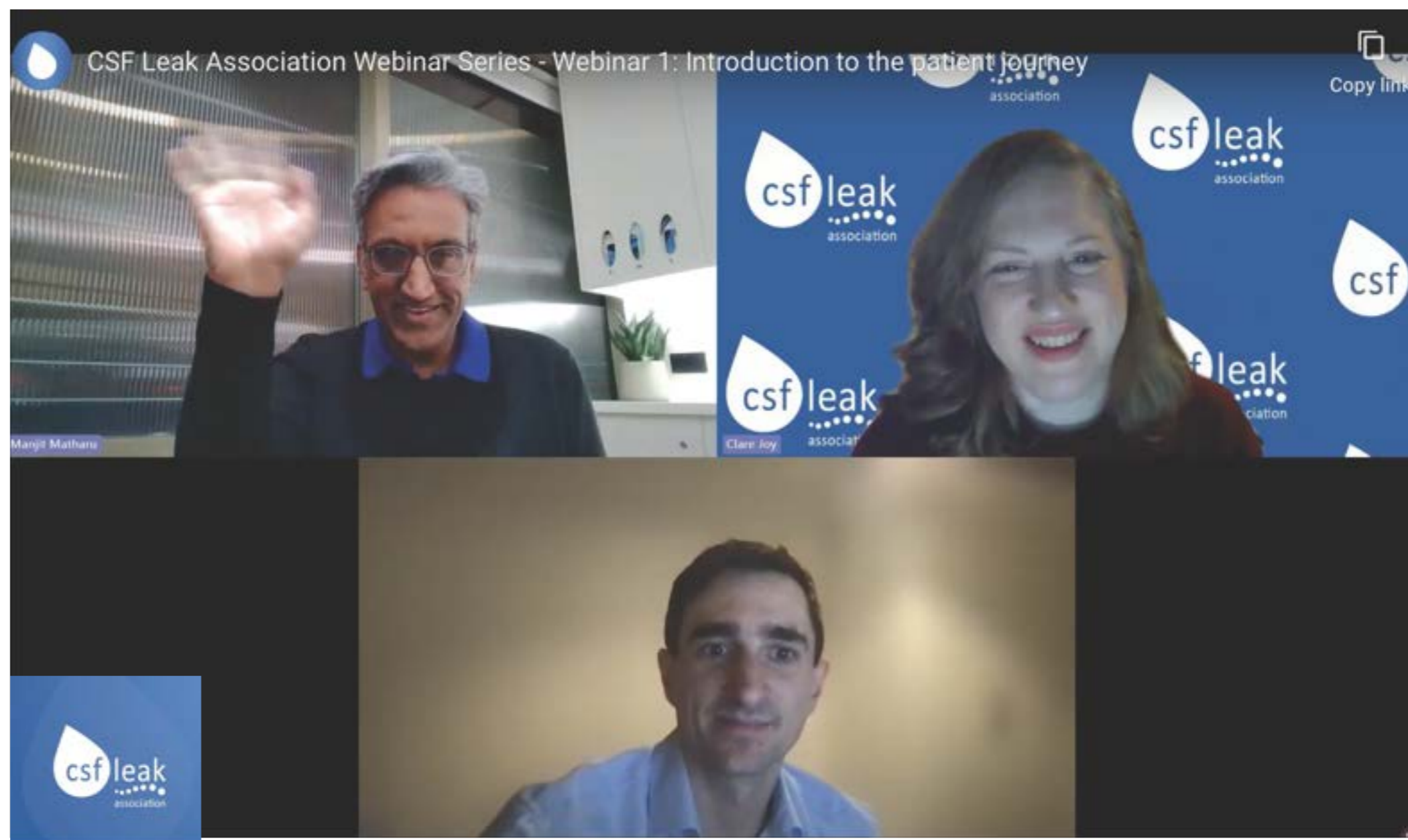


Dr Cheema gave a well-aimed and well-received presentation of the SIH guideline. Following the presentation there was an opportunity for attendees to ask questions and broaden their knowledge.

This year, we celebrated the launch of the first of our webinar series to increase understanding of the content of the SIH guideline, which the CSF leak Association has worked hard to provide for patients and other interested parties. This gave much needed clarity and detailed explanations to patients who had the opportunity to ask questions directly to CSF leak experts. The first Webinar was an Introduction to the patient journey. We were delighted that our first speaker was Dr Sanjay Cheema, first author of the world's first guidelines on the management of SIH. He took us through an overview of the condition, and a whistlestop tour of the guideline itself., including symptoms, diagnosis treatment and management. Prof Matharu conducted the Q&A.

In Webinar 2 Clinical assessment and differential diagnosis of SIH, we continued along the patient pathway, with Dr Brendan Davies taking us through the process by which specialists decipher diverse symptoms, confirm CSF leaks, and explore alternative diagnoses. The aim was to demystify what can feel like a frustrating and often frightening patient journey. Dr Davies is a Consultant Neurologist and Clinical Lead for Neurology at University Hospitals of North Midlands, with a special interest in headache and facial pain disorders, co-author of both the NICE CG150 management guidelines for headache disorders and the consensus guideline on the diagnosis and management of SIH. He was joined by Dr Cheema for the Q&A.

Webinar 3 Imaging in the management of CSF leak disorders was delivered by Dr Indran Davagnanam, a Consultant Neuroradiologist and member of the CSF Leaks MDT at the National Hospital for Neurology and Neurosurgery in Queen Square, London. Doctor Davagnanam took us through the imaging techniques commonly used in diagnosing and managing CSF leaks. Getting the right imaging at the right time, and having those tests interpreted by people with expertise in this field, can make a huge impact on outcomes. This webinar was of great interest and benefit to our community.



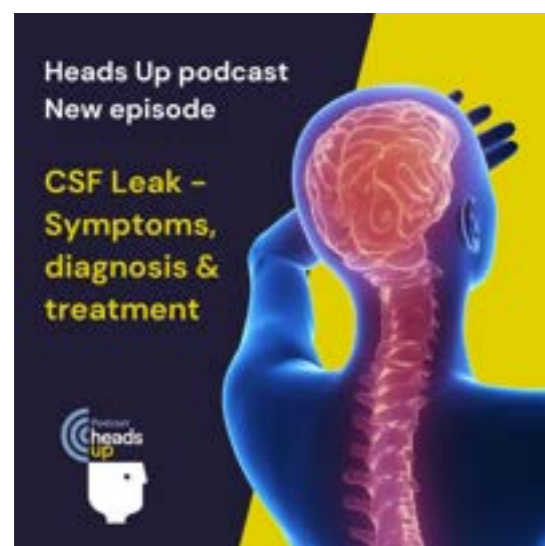
Webinar 4 on 'Procedures' was presented by Doctor Patrick Nicholson, a Neurointerventional Radiology Consultant at the Beaumont Hospital, Dublin, and Honorary Clinical Associate Professor at University College Dublin. With over 100 published papers in the field, Doctor Nicholson has extensive expertise. in both the diagnosis and treatment of CSF leaks. The webinar took us through initial treatment options, including epidural blood patches and the different procedures available. Having these performed by clinicians with expertise in this field, can make a huge impact on outcomes.

All respondents to our feedback questionnaires reported that the information presented was relevant to understanding their CSF leak and would recommend the webinars to others with a CSF leak. This is an encouraging start and we will use what we have learned and the feedback to shape future webinars.

These webinars have increased understanding of CSF leak diagnosis, treatment and management meaning that more patients will understand how to get the help they need and to how to have their CSF leak recognised and cured.

In an episode of the Practical Neurology Podcast that is essential listening for all parties with an interest in CSF leak, CSF dynamics, and headache. Prof Manjit Matharu, Dr Indran Davagnanam and Mr Parag Syal, all members of the special interest group who wrote the SIH guideline, discussed key elements of the guideline with Amy Ross-Russell, making it clear to practitioners what needs to be done to diagnose and treat spinal CSF leak and CSF venous fistula.

CSF leak Association trustee, Bern worked tirelessly throughout the year to bring attention to CSF leaks and the problems faced by patients especially those in areas with no specialised CSF leak services. As a guest of Dr Katy Munroe who is a trustee of the National Migraine Centre and host of the award winning Heads up Podcast she discussed her experience of having a CSF leak and the difficulties she encountered trying to access appropriate care. In an eye opening article 'When doctor becomes patient' published by the British Association of the Study of Headache (BASH) Bern addressed fellow doctors explaining how the experience affected her and motivated her to become a trustee of the CSF Leak Association.



Going above and beyond trustee duties Bern signed up to do a wing walk to raise awareness and funds in support of a patient registry. Delayed twice due to bad weather the wing walk was finally accomplished in the spring of 2025!

Supporting the Neurological Alliance

As members of the Neurological Alliance, the CSF Leak Association proudly supported the Back the 1 in 6 campaign, which advocates for the 1 in 6 people in the UK living with a neurological condition. By aligning with this national initiative, we amplified the voice of CSF leak patients within a broader neurological context, helping to:

- * Raise Awareness: The campaign spotlighted the challenges faced by those with neurological conditions, including CSF leaks, increasing public and policymaker understanding.
- * Drive Policy Change: Our involvement contributed to calls for improved access to timely diagnosis, specialist care, and equitable treatment pathways—key issues for CSF leak patients.
- * Empower Patients: Through shared stories and advocacy, patients felt seen and supported, reducing isolation and encouraging engagement with healthcare services.
- * Strengthen Collaboration: Working alongside other neurological charities, fostered knowledge expanded and strengthened our collective voice in influencing NHS priorities.

This collaboration helped ensure CSF leaks were not overlooked in national conversations about neurological health, reinforcing our mission to improve outcomes for all affected individuals.



Amplifying the Voice of CSF Leak Patients

As part of our ongoing collaboration with the Neurological Alliance, we actively supported the My Neuro Survey 2024/25 the UK's largest patient experience survey for people living with neurological conditions. This year's survey included tailored versions for adults, children, and carers, ensuring a wide range of voices were heard.



By promoting participation among our community, we helped ensure that the experiences of those affected by CSF leaks were captured in national data. The findings highlighted critical gaps in diagnosis, treatment, and mental health support, and will inform future advocacy and service improvement efforts. Our involvement strengthens our commitment to evidence-based change and ensures CSF leaks remain visible in national healthcare conversations.

Responding to Stakeholder Needs

When physicians, patients, and carers told us they needed a faster, clearer way to access key information in the SIH Guideline, We set out to bring this to life, we partnered with Costello Medical, specialists in translating complex clinical data into powerful, easy-to-understand formats, who generously provided £12,000 worth of pro bono support. Working together on the project, by the end of the year the full guideline was being transformed into two vibrant infographics, one for clinicians and one for patients and carers, designed to put vital insights at everyone's fingertips. It's a step that not only makes our work more accessible but also brings it closer to the people it's meant to reach. We are keen to disseminate these resources to where they can be of use to as many of our beneficiaries as possible.



As the year drew to a close, the NHS underwent significant structural changes, including the disbanding of several national programmes and teams. While this marks the end of a chapter, it also signals a year of transformation and opportunity ahead. The CSF Leak Association remains committed to navigating this evolving landscape, ensuring that the voices of patients affected by CSF leaks continue to be heard, and that progress toward equitable, evidence-based care is not only maintained but accelerated.

THE FIGHT FOR BETTER CARE

Progress at a difficult time

Turning the tide on CSF leak patient care means policymakers must take responsibility for addressing the requirements of CSF leak patients and provide the best practice healthcare patients need to prevent suffering and harm.

We've been campaigning and working hard for a consistent treatment pathway for CSF leak patients for many years. This year eighteen months after publication of the guideline we hear of more patients being accurately diagnosed with a CSF leak, as awareness of the radiological signs grows amongst neuroradiologists; this is a step forward in our aim to make sure everyone receives the treatment they need to fix their CSF leak, to end their suffering and transform their quality of life. However, delays in the system are undermining progress. Patients typically wait several months to see specialists, further waits for diagnostic scans, then follow ups and then still more waiting to receive the necessary treatments. We'll keep pushing all four NHS systems and governments of the United Kingdom to make the right choices and provide specialist centres for CSF leak patients - to deliver swift, accurate, diagnosis and effective treatments to all individuals with CSF leaks in order to secure a better healthier future for CSF leak patients.

The first step to turning things around.

We're keeping a close eye on progress.

"Raising the profile of intratentorial superficial siderosis is always on the agenda. Life now revolves around symptom management, which at times can be very difficult, but I feel it's important to get the word out and emphasise how important it is to have a CSF leak repaired as soon as possible."

[Read Ryhs's full story on the website](#)



OUR IMPACT AT A GLANCE

Together, we changed lives in 2024-5. Here are some of our highlights.



→ **£43,000**

raised to provide vital support and fund life-changing research – that's over 60% higher than last year.

→ **OVER 9,000**

Total followers across all media channels, each represents supporters, patients, caregivers, advocates, clinicians and change-makers. This is a powerful sign that awareness of CSF leaks is expanding, more voices are heard, more stories shared and more patients connected and supported, and trustworthy information provided where it's most needed. With every new follower, we amplify awareness, reduce isolation and build a stronger, more informed community that drives real change.

40,000



Page views on our web site helping people to find out more about CSF leaks, and getting us further towards our vision of a world where they cause no suffering and do no harm..

→ **199,000**

Interactions on the website, showing effective content engagement and guidance to information and resources for the CSF leak community.

OVER 100,000 ↓ **2,500**

Visitors to our 'find a doctor page', listing specialists with an interest in CSF Leaks. Enabling individuals to gain faster diagnosis better treatment outcomes and a clearer path to recovery.



views of our cartoon: What is a CSF Leak? Is a massive milestone reached this year. Helping people new to the condition understand CSF leak symptoms and why people need to lie down. Helping sufferers explain to family and friends and raise general awareness of CSF leaks.

↘ **97,000**

Downloads of the Multidisciplinary Consensus Guideline for the Diagnosis and Management of SIH, which is in the top 5% of all research outputs and cited in 62 research publications. Demonstrating the guideline's high impact and credibility: widely recognised, trusted by experts, and shaping clinical practice and ongoing research worldwide.

↓ **OVER 29,000**

Annual views of our videos on YouTube showing a sustained demand for trustworthy content. These views reflect real people— patients, caregivers, and healthcare providers actively seeking information. Our videos raise awareness, promote earlier diagnosis, and empower viewers with knowledge, potentially improving outcomes and reducing suffering for those affected by CSF leaks.

→ **8 VOLUNTEERS**

Volunteers, 8 trustees and 9 medical experts gave many hours of their free time and their expertise to run the website, post on social media, answer queries, attend conferences, policy meetings and training events, produce webinars, design awareness materials, give presentations, work on a patient registry and a European guideline. All working to increase awareness and understanding of CSF leaks and develop trusted information resources and disseminate the knowledge to reduce suffering experienced by individuals with CSF leaks.

→ **4,000**

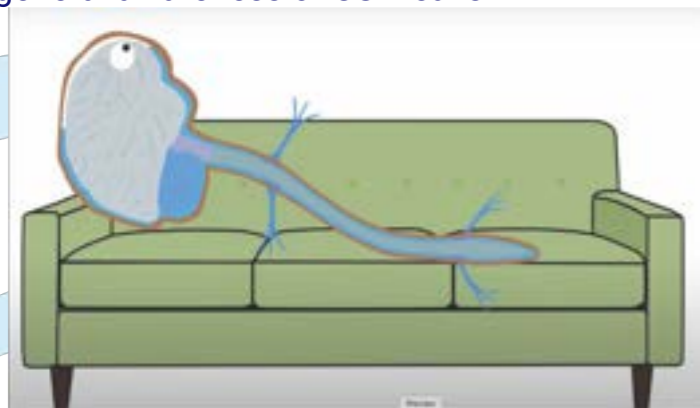
Visitors to our 'Aftercare of a CSF leak Treatment' page. Providing helpful guidance for patients for the best chance of a full recovery from treatments.



Personal patient support sessions provided online by specialist counselors 'These sessions were a god send. You struggle on trying to get some progress, you find there is no one there and most doctors have no experience or understanding of the condition.'

→ **150** Individuals supported directly from worldwide website inquiries.

75 →



RESEARCH IMPACT TO 2025

Research is key to
improving lives.

This year, we've worked closely with top clinicians and scientists to push forward understanding of CSF leaks. Every study, every collaboration brings us closer to faster diagnoses, better treatments, and improved outcomes for those affected.

WORK WE PUBLISHED IN 2022

Patient experience of diagnosis and management of spontaneous intracranial hypotension: a cross-sectional online survey. Cheema S, Joy C, Pople J, Snape-Burns J, Trevarthen T, Matharu M. *BMJ Open* 2022;12:e057438. doi:10.1136/bmjopen-2021-0

The world's first published survey of the experience of patients with SIH. **Conclusions:** SIH is a highly disabling disorder, affecting multiple domains, including pain, mobility, activities of daily living, financial circumstances and employment. Diagnostic delay and misdiagnosis are common, and currently there is a lack of consistency in the investigation and management of SIH in the UK.

Survey of healthcare professionals' knowledge, attitudes and practices regarding spontaneous intracranial hypotension

S Cheema, J Anderson, C Duncan, I Davagnanam, P Armstrong, N Redfern, A Ordman, L D'Antona, J Nissen, P Sayal, E Vaughan-Huxley, S Lagrata, V Iodice, J Snape-Burns, C Joy, M Matharu 2022, *BMJ Neurology Open*

To the best of our knowledge, this is the world's first published research on healthcare professionals understanding of SIH. **Conclusions:** We have identified a lack of awareness of SIH among non-specialists, several barriers to optimal treatment of SIH and a variation in current management pathways. The results highlight the need for education of healthcare professionals about SIH and the development of clinical practice guidelines to enable delivery of optimal and equitable care for patients with SIH.

RESEARCH CITING OUR WORK UP TO 2025

The impact of spontaneous intracranial hypotension on social life and health-related quality of life. Jesse CM, Häni L, Fung C, Ulrich CT, Schär RT, Dobrocky T, Piechowiak EI, Goldberg J, Schankin C, Sintonen H, Beck J, Raabe A. *Journal of Neurology*. 2022;269(10):5466–5473. doi: 10.1007/s00415-022-11207-7

Diagnosis and treatment evaluation in patients with spontaneous intracranial hypotension. Mehta D, Cheema S, Davagnanam I, Matharu M. *Frontiers in Neurology*. 2023;14:1145949. doi: 10.3389/fneur.2023.1145949. [frontiersin.org]

Patient experience of spontaneous intracranial hypotension (SIH): qualitative interviews for concept elicitation.

Amrhein TJ, McFatrach M, Ehle K, Malinzak MD, Gray L, Kranz PG, Weant EH, Zigler CK. *Journal of Patient-Reported Outcomes*. 2023;7:82. doi: 10.1186/s41687-023-00625-4.

Quality of Life in Patients With Confirmed and Suspected Spinal CSF Leaks.

Liaw V, McCreary M, Friedman DI. *Neurology*. 2023. doi: 10.1212/WNL.0000000000207763. [europepmc.org]

Spontaneous intracranial hypotension.

Cheema S, Mehta D, Qureshi A, Sayal P, Kamourieh S, Davagnanam I, Matharu M. *Practical Neurology*. 2024;24(2):98–105. doi: 10.1136/pn-2023-003986.

Don't delay, but don't despair: symptom duration, comorbidity and outcome after closure of spinal cerebrospinal fluid leaks.

Volz F, El Rahal A, Fung C, Shah M, Lützen N, Urbach H, Beck J, Wolf K. *Journal of Neurology*. 2024;271:2776–2786. doi: 10.1007/s00415-024-12242-2. [link.springer.com]

Optic Nerve Sheath MR Imaging Measurements in Patients with Orthostatic Headaches and Normal Findings on Conventional Imaging Predict the Presence of an Underlying CSF-Venous Fistula.

Schievink WI, Maya MM, Tay ASS, Nisson PL, Acharya J, Taché RB, Nuño M. *American Journal of Neuroradiology*. Published online March 14, 2024. doi: 10.3174/ajnr.A8165.

Impact of Spinal CSF Leaks on Quality of Life and Mental Health and Long-Term Reversal by Surgical Closure.

Volz F, Wolf K, Fung C, Carroll I, Lahmann C, Lützen N, Urbach H, Klingler JH, Beck J, El Rahal A. *Neurology: Clinical Practice*. 2024;14:e200272. doi: 10.1212/CPJ.0000000000200272.

Health-related quality of life, work ability and disability among individuals with persistent post-dural puncture headache.

Kapan A, Waldhör T, Schiffler T, Beck J, Wöber C. *The Journal of Headache and Pain*. 2024;25:64. doi: 10.1186/s10194-024-01765-8.

RESEARCH CITING OUR WORK UP TO 2025 CONT.

Improvement of health-related quality of life after closure of spinal CSF leaks in patients with spontaneous intracranial hypotension.

Jesse CM, Schär RT, Petutschnigg T, Goldberg J, Dobrocky T, Piechowiak EI, Schankin CJ, Sintonen H, Raabe A, Häni L. *Journal of Neurosurgery: Spine*. 2024;41(3):452–458. doi: 10.3171/2024.4.SPINE231232.

Assessing the effects of spontaneous intracranial hypotension on quality of life, work ability and disability.

Kapan A, Waldhör T, Wöber C. *Wiener klinische Wochenschrift*. 2025;137:148–162. doi: 10.1007/s00508-024-02423-4.

More than a headache—somatic and mental symptom burden in spontaneous intracranial hypotension before and after surgical treatment.

Volz F, Lahmann C, Wolf K, Fung C, Shah MJ, Lützen N, Urbach H, Zander C, Beck J, El Rahal A. *Frontiers in Neurology*. 2024;15:1421579. doi: 10.3389/fneur.2024.1421579.

The Challenges of Patients with Spinal CSF Leaks in Canada: A Cross-Sectional Online Survey.

Hoydonckx Y, Peng P, Vydt C, Amoozegar F. *Canadian Journal of Neurological Sciences*. Published online 13 November 2024. doi: 10.1017/cjn.2024.187.

Expert consensus on diagnosis and treatment of spontaneous intracranial hypotension.

Neurologist Branch, Chinese Medical Doctor Association; Headache and Sensory Disorders Committee, Chinese Research Hospital Association; Wu Liyong, Yu Shengyuan, He Feifang. *National Medical Journal of China (Zhonghua Yixue Zazhi)*. 2024;104(43):3943.

Defining the typical characteristics of orthostatic headache in patients with spontaneous intracranial hypotension.

Mehta D, Cheema S, Glover S, Qureshi AM, Davagnanam I, Kamourieh S, Sayal P, Toma A, Lagrata S, Joy C, Duncan C, Anderson J, Davies B, Dorman PJ, Angus-Leppan H, Walkden J, Rohrer J, Matharu MS. *Cephalalgia*. 2025;45(1):1–10. doi: 10.1177/03331024241308154.

Intracranial pressure monitoring in patients with spontaneous onset of orthostatic headache.

D'Antona L, Cheema S, Mehta D, Bremner F, Watkins LD, Toma AK, Matharu MS. *The Journal of Headache and Pain*. 2025;26:27. doi: 10.1186/s10194-024-01928-7.

Diagnosis and Management of Spontaneous Intracranial Hypotension Due to a CSF Leak: A Case of Spontaneous Recovery.

Elamin H, Pervez MN, Gordon F. *Cureus*. 2025;17(1):e77960. doi: 10.7759/cureus.77960.

Knowledge, Attitudes, and Practices Toward Orthostatic Intolerance Among Surgical Medical Staff in Chongqing, China: A Web-Based Cross-Sectional Study.

Yi H, Tang W. *International Journal of Clinical Practice*. 2025; Article ID 6622089. doi: 10.1155/ijcp/6622089.

Development and validation of a predictive model for PACU hypotension in elderly patients undergoing sedated gastrointestinal endoscopy.

Wang Z, Ma J, Liu X, Gao J. *Aging Clinical and Experimental Research*. 2024. doi: 10.1007/s40520-024-02807-6.

Spontaneous intracranial hypotension

Sarah Palmer

2022, *British Journal of Neuroscience Nursing*

WORK WE PUBLISHED IN 2023

Multidisciplinary consensus guideline for the diagnosis and management of spontaneous intracranial hypotension.

Cheema S, Anderson J, Angus-Leppan H, Armstrong P, Butteriss D, Carlton Jones L, Choi D, Chotai A, D'Antona L, Davagnanam I, Davies B, Dorman PJ, Duncan C, Ellis S, Iodice V, Joy C, Lagrata S, Mead S, Morland D, Nissen J, Pople J, Redfern N, Sayal PP, Scoffings D, Secker R, Toma AK, Trevarthen T, Walkden J, Beck J, Kranz PG, Schievink W, Wang SJ, Matharu MS. *Journal of Neurology, Neurosurgery & Psychiatry*. 2023;94(10):835–843. doi: 10.1136/jnnp-2023-331166.

Groundbreaking world's first published clinical guideline for SIH. **Conclusions:** This guideline has the potential to stimulate research, increase awareness of SIH among healthcare professionals, produce greater consistency in care, improve diagnostic accuracy, promote effective investigations and treatments and reduce disability attributable to SIH.

RESEARCH CITING OUR WORK UP TO 2025

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WHY THIS MATTERS

Our dedication to research is transforming understanding and care for patients with CSF leaks. By funding and supporting landmark studies, including clinician and patient surveys, with quality of life research, and the development of multidisciplinary SIH guidelines—the CSF Leak Association has driven improvements in diagnosis, imaging, and treatment. These efforts continue to shape clinical practice, influence policy, and be cited in leading journals, underscoring the urgent need for sustained investment in SIH research, to ensure equitable, evidence-based care for all affected. Globally, this growing evidence base empowers clinicians, informs healthcare systems, and drives meaningful change. Our commitment to research ensures that lived experience and clinical expertise work together to build a better future for CSF leak patients.



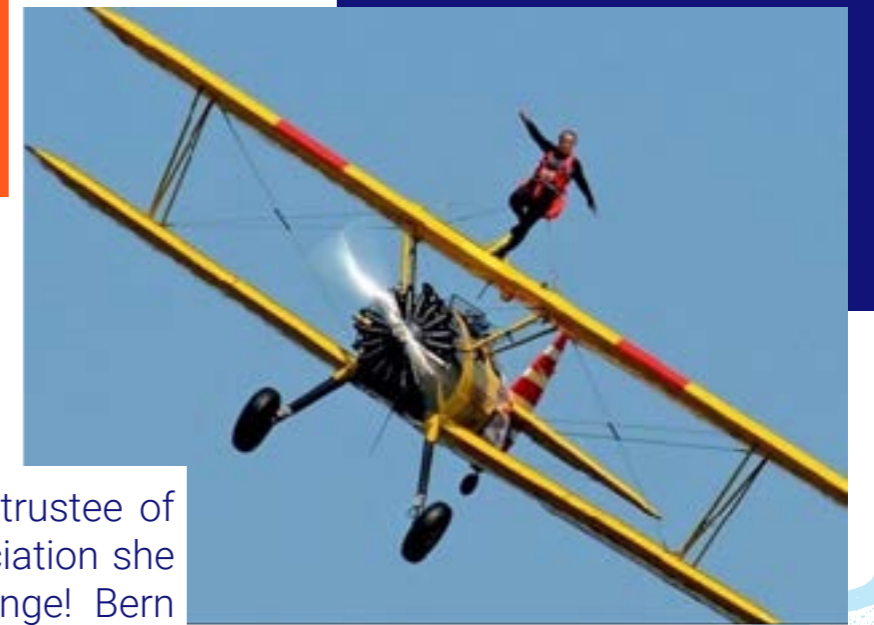
← JED, CAM AND HARJOT

We are extremely grateful to Jed and his friends Cam and Harjot for raising an amazing £1,500. The trio challenged themselves to run 107km across the length of Luxembourg over 3 days. They also organised an article that was published in a Luxembourg news outlet RTL about the run, to shine a light on the devastating effect CSF leaks have on individuals. What an incredible achievement!



← LUCY & SIMON

Huge thanks go to Lucy and Simon for cycling 100 miles to raise funds. The husband and wife team took on the Ride London Cycle challenge and raised £1,481. Lucy said 'knowing that you are supporting people with CSF leaks while on my bike gave me so much motivation to keep cycling'. Thank you so much to Lucy and Simon for taking on this epic challenge and their ongoing support of the CSF Leak Association.



BERN →

Not only a GP and trustee of the CSF Leak Association she also loves a challenge! Bern 'standing up for leakers' raised £2,261. Huge thanks to her for brave wing walk to help fund a patient registry, a project she is keen to support.

↓ KATE

Despite never having cycled more than a few miles before Kate took on the enormous challenge of cycling 100 miles in Ride London to support people with CSF leaks. Kate raised over £900 She smashed it!

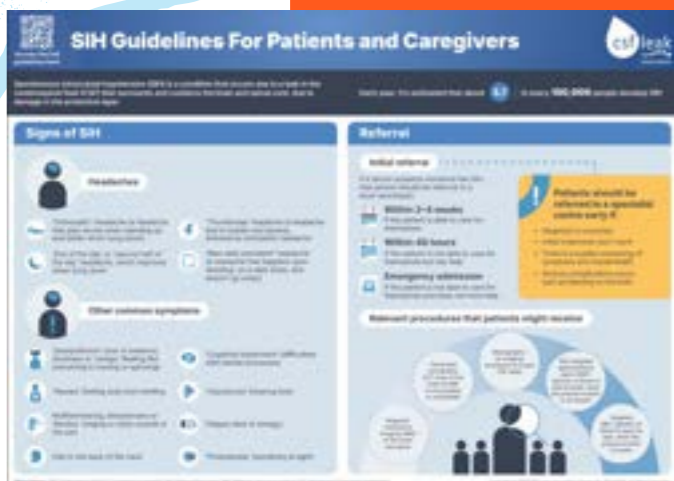


FUNDRAISER DONORS

We are extremely grateful for all the generous individuals who contributed to these fundraisers efforts.

← COSTELLO MEDICAL UK

We are deeply grateful for their generous pro bono support in developing two infographics illustrating the guideline for SIH. Their contribution, valued at £12,327 has been invaluable in advancing awareness and understanding of CSF leaks.



THANK

YOU

→ MATHEW

After suffering a spontaneous cranial CSF leak Mathew was motivated to raise funds and raise awareness by running over several days and he raised an astonishing £540. His determination to support others is inspiring. Well done Matt you are a star!



THANK

YOU

TO ALL OUR MEMBERS

We extend our heartfelt thanks to each and every one of our members for your continued support and subscriptions over the past year. Your commitment enables us to pursue our mission: to ensure swift and accurate diagnosis, effective treatment, prevention, and holistic support for all those affected by CSF leaks. Your membership is more than a subscription—it's a statement of solidarity with a growing community determined to improve outcomes, raise awareness, and advocate for better care. Together, we are driving change, empowering patients, and influencing policy to ensure that no one faces a CSF leak alone. Thank you for standing with us.

TO ALL OUR VOLUNTEERS

Our dedicated volunteers are at the heart of the CSF Association. Their commitment, compassion and generosity ensure that our support, information, and advocacy reach those who need it most. In 2024/25 eight remarkable individuals gave their time and energy to support people affected by CSF leaks. Working at home, each contributed in meaningful and diverse ways, from providing direct support and attending events, to producing webinars, raising awareness, and engaging with clinicians and partner organisations. Their passion and dedication strengthen our mission and expand our reach. Thanks to their tireless efforts, we are able to improve healthcare and enhance the lives of those living with CSF leaks. We are deeply grateful to each of our volunteers. Their unwavering support makes our work possible and we simply couldn't do it without them.

PERSONAL DONORS

We extend our heartfelt thanks to every individual who has supported us this year. Whether through one-time gifts or ongoing support, your contributions have helped us continue our vital work to raise awareness and improve healthcare for people with CSF leaks. Your generosity, belief in our mission, and commitment to making a difference have been truly inspiring. Together, we are building a future where CSF leaks are better understood and more people are effectively treated—and we couldn't do it without you. Thank you for your support

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PATIENT EXPERIENCE WRITERS

Thank you to all who shared their experience by writing their patient stories for the website. This is a powerful way to help others makes sense of their symptoms to give hope and empower them to seek appropriate healthcare.

**THANK
YOU**



OUR PLANS FOR 2026

In the coming year, and beyond, we'll be working tirelessly to increase awareness and understanding of CSF leaks.



We'll continue to work towards understanding the causes and consequences of health inequality in CSF leak healthcare and do everything in our power to close the gap. We will invest in an ambitious and innovative patient registry a significant step towards further research into the causes and treatments to find the best treatment options, and will support the push for more people to receive effective

PREVENTING CSF LEAKS: CAMPAIGN FOR SAFER PRACTICE

As part of our commitment to improving patient safety and outcomes, we will launch a campaign focused on the prevention of CSF leaks. This initiative will aim to raise awareness among healthcare professionals and institutions about best practices in procedures that carry a risk of causing CSF leaks, particularly lumbar punctures and epidurals.

We will advocate for the widespread adoption of atraumatic (non-cutting) needles, which have been shown to significantly reduce the risk of post-procedural CSF leaks. Patients undergoing these procedures should be fully informed of the potential risks, symptoms of CSF leaks, and the importance of post-procedure monitoring with clear, accessible information. We will support this campaign by providing information and resources to patients and healthcare professionals alike.

UNDERSTANDING CSF LEAKS & DEVELOPING PATIENT REGISTRY

Understanding the real-world experiences of people affected by CSF leaks is central to our mission. We will continue to develop our patient registry alongside our research partners, UCLH. The registry will be a vital tool for capturing the diagnostic journeys, treatment outcomes, and lived experiences of individuals across the UK.

The registry will yield a strengthened evidence base for advocacy, research, and service improvement. The anonymised data collected will support clinical research into diagnosis, treatment efficacy, and long-term outcomes – helping to drive innovation and improve care. Just as importantly, the registry empowers patients to shape future care pathways and influence policy decisions.

Our next steps include enhancing data collection tools, improving accessibility for participants, and collaborating with clinicians and researchers to ensure the registry meets both patient and scientific needs.



PROGRESS

We'll deepen our engagement with the medical community to improve outcomes for people affected by CSF leaks. We plan to attend more conferences across key specialties, we'll share best practices and foster collaboration.

We'll build stronger partnerships with professional bodies to embed CSF leak awareness and understanding into clinical education. Our SIH Guideline infographic for clinicians will be distributed widely to promote excellence in care.

We'll also continue to champion research and innovation, ensuring lived experience helps shape future practice.

TACKLING INEQUALITY

Expanding Public Health Outreach

We'll broaden our public health outreach to ensure that everyone affected by a CSF leak has access to clear, compassionate, and reliable information. Our patient-friendly infographics explaining symptoms, diagnosis, and care pathways in simple, accessible language will be widely shared through social media, community events, and strategic partnerships. Importantly, we will continue to listen to patient feedback to refine our materials and ensure they reflect real-world needs and experiences.

Our goal is to build a more informed and empowered community, where no one is left behind. We are committed to ensuring that access to best-practice healthcare is not limited to those living in areas with knowledgeable specialists or those who can afford private consultations, scans, and treatments. Everyone with a CSF leak deserves timely, effective care. By raising awareness and advocating for equitable access, we aim to prevent unnecessary suffering and harm.

STRENGTHEN EUROPEAN COLLABORATION

We'll continue working with partners across Europe to advance a multidisciplinary guideline for CSF leaks, one that reflects both clinical expertise and lived experience.

We'll contribute patient insights, support cross-border dialogue, and advocate for guideline adoption to reduce variation in care and improve access to treatment. Through conferences, webinars, and translated materials, we'll help share best practice widely. Building a more consistent, patient-centred approach to care across Europe.



GET INVOLVED

Without you, we couldn't achieve our vision of a world where every CSF leak is treated swiftly and effectively. Here are some of the ways you can be part of our fight.

Donations

Your donations help us fund everything from campaigns and support. Thank you.

<https://csfleak.uk/about-us/donations>

Become a member

Help us make sure more and more people get the support and care needed to locate and treat their CSF leaks.

Challenge yourself

Whether it's walking, running or cycling, we have a range of fundraising events to get involved with both in person and virtual.

Shop online

Help us prevent CSF leaks by joining Easyfundraising for free. Every time you shop, the retailer will make a donation to CSF Leak Association at no extra cost to you whatsoever!

<https://www.easyfundraising.org.uk/causes/csfleak/>

Volunteer your time

Support campaigns, or raise awareness. Our volunteers are the backbone of our organisation.

volunteer@csfleak.uk

Leave us a gift in your Will

Income from gifts people leave us, would make so much more work possible.

Philanthropists, charitable trusts and foundations

Help us fund a patient registry. Find out how you, your charitable trust or foundation can help by contacting. office@csfleak.uk

Corporate partners

Help raise awareness of CSF leaks and provide vital support to those affected. If you'd like to team up, get in touch at office@csfleak.uk



Find out how to get involved at csfleak.uk/volunteering



HOW WE'RE RUN

Our governance and financial statements

Financial review

Overall

This year has been one of growth, resilience, and meaningful progress for the CSF Leak Association. With a clear focus on impact, we continued to raise awareness, support patients, and invest in projects that bring us closer to earlier diagnosis and better care for those affected by CSF leaks. Thanks to the generosity of our supporters and careful financial stewardship, we have ended the year in a strong position, with a surplus that enables us to expand our impact in the year ahead. Our income increased significantly thanks to a successful grant and continued support from donors and fundraisers. This reflects the growing recognition of our work and the generosity of those who believe in our cause.

We maintained a careful approach to spending, ensuring that funds are directed where they could make the greatest difference. Importantly, the charity has no paid staff and no office costs. All work is carried out by volunteers and expert contributors who generously give their time and skills- pro bono. This includes clinical advisors, digital professionals, trustees, and patient advocates. Their contribution is invaluable and allows us to achieve far more than our financial resources alone would permit.

Income

Income grew compared to the prior year by £16,736, to £43,401 driven primarily by growth of £15,150 in grant fundraising which rose to £25,000 representing a grant from the Margret Butters Reekie Trust for the patient registry. Corporate donations increased from zero in 2024, to £4,000 in 2025 with a donation from Integra Life Sciences for donations to the charity from delegates at two conferences in the year. In 2025 membership grew steadily to provide an income of £2,541 an increase from the previous year of £556.

This increase in financial support is a powerful reminder that our message is resonating and that with continued generosity, we can meet our charitable objectives and build a brighter future for those we serve.

Expenditure

In 2024/25, our total expenditure was £15,474 representing a reduction of £2,204 compared to the previous year's spend of £17,678. This decrease reflects the conclusion of National Lottery-funded counselling sessions and cost savings achieved through more efficient website management. Despite the reduction in spend, we continued to prioritise activities that directly support our charitable objectives. We invested £10,326 in website and IT improvements, enhancing the security, functionality, and accessibility of our digital platforms.

The website continues to act as a lifeline for many, offering trusted information, signposting to care, patient stories, practical advice, and access to our contact us helpline. Our digital presence remains central to our mission of supporting those affected by CSF leaks. We spent £2,805 on the CSF Links mental health support project, that continued to provide counselling sessions to help individuals manage the emotional impact of CSF leaks. Although the number of sessions reduced following the end of specific grant funding, the service remains a part of our support offering. A further £2,343 was allocated to awareness and education activities. We attended several key medical conferences and produced a series of webinars presented by CSF leak experts to help patients better understand and engage with the clinical guideline. Our medical advisors also appeared on podcasts to reach a wider audience and raise awareness of the condition.

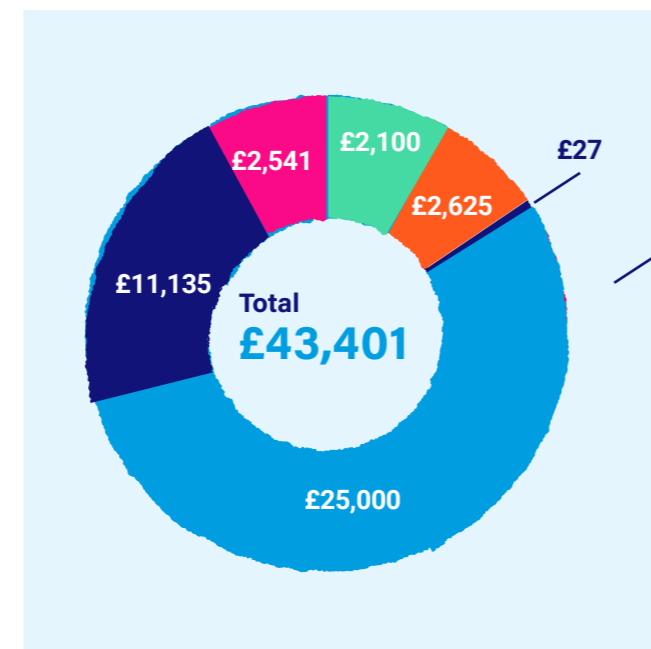
Administrative, insurance, and fundraising costs were kept to a minimum, in line with our commitment to maximise the impact of every pound spent. Our volunteer-led model and use of digital tools continue to ensure that resources are directed where they are needed most.

Reserves and Surplus

We achieved a net surplus of £27,927, increasing our total funds from £68,477 to £96,404. This includes designated and restricted funds for future research projects and the patient registry.

INCOME AND EXPENDITURE

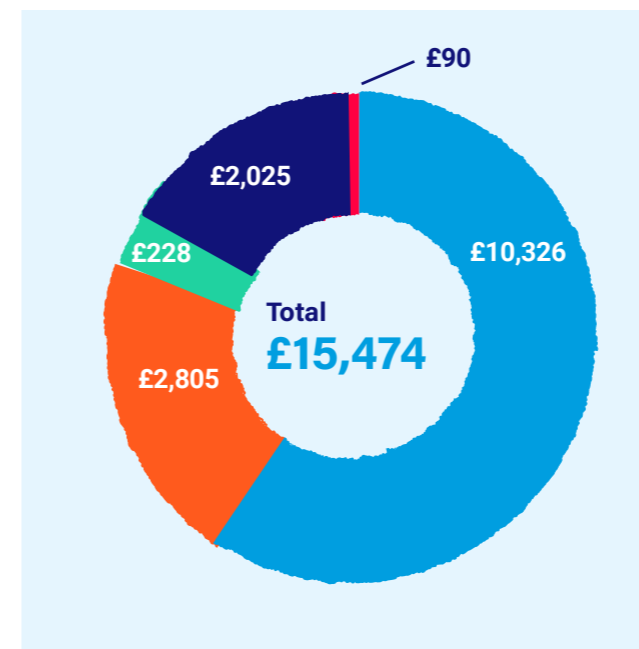
Income



- Grants
- Donations
- Income from investments
- Fundraising activities
- Membership
- Other trading activities

We continue to meet our reserves policy of holding at least eight months of operational costs. as part of a planned effort to conserve funds and increase the amount we hold in reserves to provide the funding needed for a patient

Expenditure



- Website IT Security
- CSF Links Support
- Awareness and Education
- Governance and cost of memberships
- Expenditure on raising funds

registry a vital means to gather data required to improve understanding and advocate for better healthcare services to individuals with CSF Leaks.. We continue to be deeply grateful for the gifts we receive from all of our supporters.

Key Achievements:

- Clinical Engagement: Major conferences attended to strengthen relationships with healthcare professionals and advocate for earlier diagnosis and better treatment pathways.
- Digital Outreach Expansion: Our online presence grew, helping us reach more patients, families, and clinicians with vital information and support.
- CSF Links Project: Continued delivery of vital mental health support for patients navigating the challenges of CSF leaks.
- Patient Registry: With focused grant funding, work has begun on a patient registry, a crucial step toward to improve patient outcomes and advance research.
- Website & Digital Tools: investment in enhanced security, efficiency, and accessibility, ensuring our resources are reliable and far-reaching.
- Webinars & Podcasts: Delivered educational outreach offering expert-led sessions on diagnosis, treatment options, and management. These resources provided the public with accessible, high-quality knowledge and direct engagement with leading specialists.
- Volunteer & Pro Bono Contributions: The dedication of volunteers and professionals donating their time ensures every pound is maximized for impact. We are particularly grateful to Costello Medical this year for the work on a guideline infographic.

This Year's Funding Impact

Thanks to generous support, we've made significant strides in raising awareness, and publicising the guidelines published in May 2023. This is leading to more people being diagnosed and receiving treatment, reducing suffering and harm whilst also reducing the burden of undiagnosed patients on society.

Looking Ahead:

Our strong financial position enables us to plan confidently for the future. We remain committed to improving the lives of individuals affected by CSF leaks and advocating for greater recognition and improved treatment for all.

We plan to use our resources wisely to:

- Fund a patient registry and research into better diagnosis and treatment.
- Advocate for widespread adoption of the SIH clinical guideline alongside recognition and understanding of the needs of CSF leak patients.
- Extend outreach to help more undiagnosed and misdiagnosed patients.
- Educate clinicians on prevention, diagnosis and treatment.
- European SIH Guideline development.
- Expand our support services.

How we manage risk

The Trustees have assessed the major risks to which the charity is exposed and are satisfied that systems are in place to mitigate exposure to those risks. The charity is covered by £5,000,000 public liability and employers' liability insurance with Zurich Insurance. A key element of our strategy focuses on risks., we continue to be cautious around expenditure on fundraising activities. We continue to review plans ensuring we are focusing on activities that will accelerate our progress at this critical time.

Not making the best strategic choices and losing sight of our strategic vision.

If we do not implement the right changes at the right time, our ability to improve the lives of those affected by CSF leaks and SIH will be limited. As we understand more about how best to achieve our objectives, regular review remains critical.

An outcome focus for 2025 has provided us with clear direction, as we face new emerging issues. We continue to focus on the goals of our strategy and be responsive to the external changes, while maintaining a longer-term vision in these challenging times. The approach also provides us with regular opportunities to review our plans and ways of working, ensuring we make best use of our assets to maximise the impact of our work.

In 2026, we will take the opportunity to further consider how we might need to evolve our organisation to achieve our ambitions and ensure they are fit for the future.

Not engaging sufficiently with those affected by CSF leaks, including those in disadvantaged groups.

To be viewed as a reliable advocate, and meet the needs of people with CSF leaks, we must engage with their experiences, insights and aspirations. A key part of planning and developing our work is ensuring we build relationships with the CSF leak community. A key focus has been reviewing and developing the ways in which we engage with those living with or affected by CSF leaks, considering how we can improve and how we communicate along with the diversity of those we connect with.

In 2026, we will build on tackling inequality by hearing more about the lived experience of people with CSF leaks in more disadvantaged groups, and how we can support them.

We also continue to use technology to our advantage, to strengthen, broaden and deepen our links to people with CSF leaks, reflecting their views and challenges in our work. Our CSF links support programme for people with CSF leaks in Scotland provides us with opportunities to learn more about how to involve and respond to the experiences of the community.

Not working effectively with agencies.

We cannot create a world where CSF leaks are swiftly diagnosed, effectively treated, prevented and all patients holistically supported alone. It is vital that we build on our relationships with key organisations, such as the NHS and government bodies within all nations. We should drive forward the needs of people with and at risk of CSF leaks in a way that recognises the inequalities, financial and capacity pressures they face daily, particularly as we move into a time of uncertainty.

Building partnerships and working with others to increase our efficacy and impact is a key aspect of our strategy. In 2026 we will continue to be active partners in movements that address inequality and social determinants of health, to help make greater impacts for those living with and affected by CSF leaks.

Assurance reviews of policies, controls and processes that are within key areas of risk management take place each year. We continue to review and implement our plans. This internal reporting provides assurance to trustees that we have identified and are managing the risks we face.

How we fundraise

We're almost entirely reliant on donations to fund our work. Without the public's generosity we wouldn't be able to push for improved healthcare provision and support for people with CSF leaks, or to support research to make advancements in the understanding of CSF leaks.

We are registered with the Scottish Fundraising Regulator and are open about how we raise our funds. We continually strive to adhere to the Code of Fundraising Practice and are committed to the Fundraising Promise. This report covers the requirements charities must follow as set out in the Charities Act 2016.

We seek to minimise the risk of breaches of fundraising compliance through training and inductions for new volunteers on the Fundraising Code of Practice and implementing compliance policies. We will proactively engage with the Fundraising Regulator and other bodies as needed to ensure that any concerns raised are addressed as a priority.

Our generous supporters raise money for us in many different ways including fundraising in their local communities. We were delighted to enter a team into the Ride London 100 mile event.

We see partnership working as a crucial route to achieving our mission. We have safeguards in place with our partners to

ensure that we do not compromise our independence in any way. We're also supported by a corporation, and a charitable trust, as well as philanthropic gifts from donors.

People can sign up to make a regular donation, or become a member via the website. We also ask people to give to us through shopping via Easyfundraising, or by leaving a gift in their Will.

Our website outlines our complaints process. In 2024 we received zero complaints about fundraising. We work to ensure we resolve, learn and take action to prevent issues happening. We prepare an internal complaints report that is shared with our trustees.

A controls framework is in place for effective internal governance of our fundraising. The Board receives regular reports on performance, compliance and plans and considers our fundraising compliance. The Treasurer looks closely at our financial performance and reviews in detail the controls we have in place relating to each area of accountability covered in the OSCR guidance on Charity trustee duties and fundraising.

How we're organised and governed

The CSF Leak Association was set up in 2016 by David Baldwin a CSF leak patient along with other CSF leak patients.

CSF Leak Association is a Scottish Charitable Incorporated Organisation (SCIO) registered with the Office of the Scottish Regulator in Scotland (OSCR), which is the independent regulator and registrar for Scotland's charities.

We work across all four nations, adapting our services as appropriate to relevant regional and local circumstances as well as need.

Our Board of Trustees

Our Board of Trustees – referred to as the Board from now on – has collective responsibility for everything we do and is responsible for:

- Our overall strategic direction, including evaluating progress against our strategic plans
- Ensuring our financial stability
- Acting in the best interests of our charity
- Ensuring that we comply with our governing documents, and any other relevant legislation.

The maximum number of trustees permitted under our Constitution is 20, and during 2024/5 they numbered between 8 and 10. Trustees are usually appointed for up to three years and may be re-appointed. The Board benefits from the wide range of skills and expertise across different

disciplines that its trustees bring, as well as personal experience of living with CSF leaks and experience as healthcare professionals.

Trustee recruitment

We recruit trustees in line with the provisions of the constitution. Membership of the Board is open to all members and elections are held at the AGM. When professional skills are required Trustees are recruited by open advertising or more targeted recruitment searches to ensure that we have the right balance of skills and experience that we need. New trustees are introduced to their new role and an induction programme is in place to ensure new trustees are aware of the scope of their responsibilities under the charities Act.

The expertise and contributions of the Trustees we appointed during 2024/5 has been hugely beneficial to the work of the Board. During the year, due to Trustees ill health and standing down early, we identified the need for some further recruitment and began work to appointing at least three new Trustees during 2024 to bring communications, digital and charity secretary expertise to the Board.

Board meetings

Our Board usually meets six times a year, all meetings are on-line due to the health restrictions of some board members and the wide geographical area of where trustees live.

Medical Advisory committees

The Chair and secretary of the medical advisory committees (MAC), usually meet 12 times a year.

Our volunteers

Our volunteers are at the heart of all we do and we are committed to providing an inclusive and supportive environment where everyone can be their best. The wellbeing of colleagues remains a key focus as we responded to the challenges posed by ill health, cost of living crisis and economic uncertainty. We provide training on a range of topics. Our work is underpinned by the principles of trust and support for colleagues to work flexibly from home valuing on line time together as needed.

Equity, diversity and inclusion

We adhere to our Equity, Diversity and Inclusion (EDI) policy in all our areas of work. We are committed to building an inclusive and diverse organisation, confidently tackling inequality. We believe that everyone should be treated equally, regardless of their religion, beliefs, age, gender, race, disability or sexual orientation.

Training, learning and development

Our learning and development offer includes a range of training opportunities, as well as opportunities to apply for funding to take part in external courses and conferences. Our funding decisions are based on relevance to a colleague's role and the needs they have identified. We have a self directed approach to training delivery, offering a suite of virtual opportunities. We continue to offer resources to support sound approaches to risk assessment, we induct new colleagues into the charity and we support personal and career development.

How we work to promote success

In order to be successful in our mission, we need to hear the voices of people with CSF leaks, our volunteers, healthcare professionals, partners and our stakeholders in everything we do. Our trustees act in a way they consider to be most likely to promote the success of the charity to achieve our mission. To do this we consider:

The long-term consequences of our decisions

We are grateful for the support of our medical advisory committee (MAC) who enable us to consider the impact of the decisions we take over the medium and long term. In 2024 we consulted with the MAC on topics including new partnerships, progress against our strategy and future plans and how we engage with healthcare professionals and policy makers.

Our strategy sets out the change we want to see for people with CSF leaks in five outcomes (page 4) and we have developed route maps that show us the best way to achieve these, meaning that we understand what our short-term actions will achieve over the long term. We also pay close attention to the external context so that we can adapt and respond as needed through 'forward thinking' exercises.

The need to act fairly

Fairness is key to achievement of these aspirations and our organisation policies reflect a consistently fair and transparent approach. We are also committed to equality in our workforce and are actively ensuring the fair treatment of colleagues.

The need for good relationships with partners, suppliers, customers and others

Our partners and suppliers are key to much of the work we do and we work hard to drive high standards and to build great relationships with them. We have clear policies on open and fair procurement and effective contract and supplier management.

The impact of what we do on the environment

We recognise our responsibility to minimise our environmental impact and we are constantly reviewing our impact on the environment as an organisation.

The benefits of maintaining a reputation for high standards of conduct

Our reputation is very important to us and to the people we support. We want to be trusted to inform and advise those who need our support and have clear standards of expected conduct for volunteers, underpinned by our values.

Trustees, officers and advisors

Board of Trustees and the membership of sub committees

**Clare Joy
Chair**

Medical Advisory Committee
Secretary

Dr Bern Hard

Medical Advisory Committee

**Adam Goldsmith,
Secretary**

**Clare Sargeant,
Treasurer**

Deborah Ogg

Anita Bellas

(Joined 7 January 2025)

Rachel Wall

(Joined 7 January 2025)

Shena Carrick

(Retired 29 October 2024)

Dr Khadeja Ali

Our warmest thanks are recorded to Shena Carrick who retired during the year due to declining health, we are deeply grateful to her for her contribution to and support of our work at Board level and in many other areas of our work. She undertook these duties to benefit others with a CSF leak despite enormous difficulties that her own health imposed.

Key stakeholders – our advisory group

Medical Advisory Committee

We are very grateful to the following permanently established advisory groups, who help us enormously, and whose meeting minutes are circulated to the Board:

Our Medical Advisory Committee (MAC) plays a vital role supporting the Trustees and helping the charity work towards and achieve its objectives.

It provides insight, scientific direction, support and expertise to the CSF Leak Association and the work it does.

The MAC works closely with the Charity's Board of Trustees and acts as a focal point for medical professionals to enable the development of clear and consistent patient pathways and advance investigatory and treatment options.

Current members of the committee are:

Prof Manjit Matharu, Consultant Neurologist, National Hospital for Neurology and Neurosurgery (Chair)

Mr James Walkden, Consultant Neurosurgeon, Aberdeen Royal Infirmary

Dr Anthony Ordman, Consultant in Pain Medicine, Wellington Hospital

Dr Changez Jadun, Consultant Neuroradiologist, Royal Stoke University Hospital

Dr Simon Ellis, Consultant Neurologist, Royal Stoke University Hospital

Dr David Butteriss, Consultant Neuroradiologist, Royal Victoria Infirmary

Dr Brendan Davies, Consultant Neurologist, Royal Stoke University Hospital

Dr Heather Angus-Leppan, Consultant Neurologist, Royal Free Hospital

Mr Ahmed Toma, Consultant Neurosurgeon, National Hospital for Neurology and Neurosurgery

Sarah Mead, Patient Representative

Clare Joy, Trustee Representative (Secretary)

If you are a medical professional with a specific interest in CSF leaks you can register your interest in joining when a vacancy becomes available by contacting the committee's secretary at mac.secretary@csfleak.uk

The Board extends heartfelt thanks to all the members of the Medical Advisory Committee for the expert advice they provide.

How our work delivers public benefit

We have a duty to report on the public benefit that we deliver under the Scottish Charities Act 2005. Taking the Office of Scottish Charity regulators guidance into consideration, the Board is satisfied that our public benefit requirements have been met.

We provide direct services and practical support to people affected by CSF leaks or with symptoms of a CSF leak. We advocate and work with healthcare professionals from a wide range of disciplines to raise awareness, educate and improve the healthcare provision of CSF leak patients in their local areas. We continue to support research building on our knowledge of CSF leaks, to improve diagnostic accuracy and effectiveness of treatments. With the aim of one day, ensuring everyone with a CSF leak receives swift accurate diagnosis and effective treatment to reduce suffering and prevent harm.

Data Protection & Privacy

We take privacy very seriously; we adhere to the principles of the UK General Data Protection Regulations and understand best practice for managing information. For that reason, we have set out a policy and a GDPR notice, so people can make sure they understand how and why we use the information they give us. Trustees and key volunteers are given GDPR and cyber security training through VSL Learning and we are registered with the Information Commissioner's Office.

Statement of trustees' responsibilities

The Board of Trustees is responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions, disclose (with reasonable accuracy) at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities and Trustee Investment (Scotland) Act 55 Contents 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and for taking reasonable steps for the prevention and detection of fraud and other irregularities. Insofar as each of the trustees is aware:

The trustees are responsible for preparing the trustees' annual report and the financial statements in accordance with applicable regulation and cash accounting methods.


Charity regulation requires the trustees to prepare financial statements for each financial year. Under that regulation, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period.

- In preparing these financial statements, the trustees are required to:
- Select suitable accounting policies and then apply them consistently.
- Comply with the requirements of Office of Scottish charity regulator (OSCR)
- Keep accurate financial records.

- There is no relevant financial information of which the charity's independent examiner is unaware.
- The trustees have taken all steps that they ought to have taken as trustees to make themselves aware of any relevant financial information and to establish that the independent examiner is aware of that information.

The trustees are responsible for the maintenance and integrity of the financial information included on the charity's website. Regulations in Scotland governing the preparation and dissemination of financial statements may differ from regulation in other areas.

Approved by the Board of Trustees of the CSF Leak Association on 8 July 2025, the Annual Report contained therein, and signed on its behalf by:



Clare Joy

Chair

CSF Leak Association

Registered office address

CSF Leak Association

Unit 110982, PO Box 26965,

Glasgow, G1 9BW

office@csfkeak.uk

CSF Leak Association is a charity

registered with the Office of the Scottish Charity Regulator

registration no: SC046319.

Bankers and professional advisors

Bankers

Royal Bank of Scotland

One Churchill Place

London E14 5HP

Independant Examiner

Alasdair Lawton

ICAEW Membership Number 7766919

**CSF Leak
Association**

**Statement of
Financial
Activity
For**

**1st April 2024 to
31st March 2025**



Receipts and payments accounts

For the period

01 April 2024 - 31 March 2025

Section A Statement of receipts and payments

	Unrestricted funds	Designated Funds	Restricted funds	Total funds	Total funds
	to nearest £	to nearest £	to nearest £	This YE 31/3/25 to nearest £	Last YE 31/3/24 to nearest £
A1 Receipts					
Donations	10,510	-	625	11,135	1,603
Grants	-	-	25,000	25,000	9,850
Receipts from fundraising activities	2,100	-	-	2,100	11,327
Gross trading receipts	27	-	-	27	33
Gross receipts from memberships	2,541	-	-	2,541	1,985
Bank interest	2,598	-	-	2,598	1,867
A1 Sub total	17,776	-	25,625	43,401	26,665
A2 Receipts from asset & investment					
From sale of investments & assets	-	-	-	-	-
A2 Sub total	-	-	-	-	-
Total receipts	17,776	-	25,625	43,401	26,665
A3 Payments					
Expenses for fundraising activities	90	-	-	90	201
Governance costs	-	-	-	-	-
Payments to charitable activities:					
Website & IT	10,326	-	-	10,326	4,881
Publish survey/guideline	-	-	-	-	4,440
Awareness	2,025	-	-	2,025	1,143
CSFLA Membership Costs	122	-	-	122	122
Insurance & PO box	106	-	-	106	106
CSF Links project	-	-	2,805	2,805	6,785
A3 Sub total	12,669	-	2,805	15,474	17,678
A4 Payments relating to asset and					
Purchases of tangible assets	-	-	-	-	-
Purchase of investments	-	-	-	-	-
A4 Sub total	-	-	-	-	-
Total payments	12,669	-	2,805	15,474	17,678
Net receipts / (payments)	5,107	0	22,820	27,927	8,987
A5 Transfers to / (from) funds					
	-	-	-	-	-
Surplus / (deficit) for year	5,107	0	22,820	27,927	8,987

APPENDIX 2

Receipts and payments accounts

Section B Statement of Balances

	Unrestricted funds	Designated funds	Restricted funds CSF Links	Restricted funds KB/Registry	Total YE 31/3/25	Total YE 31/3/24
	nearest £	nearest £	nearest £		nearest £	nearest £
B1 Cash funds						
Balance at start of year	13,873	50,000	3,065	1,539	68,477	59,490
Surplus/(deficit) from receipts and payments account	5,107	-	(2,805)	25,625	27,927	8,987
Movement in funds	(10,000)	10,000	-	-	-	-
Cash and bank balances at end of year	8,980	60,000	260	27,164	96,404	68,477

Signed by one or two trustees on behalf of all the trustees

Approved Date	Signature	Print Name
21/06/2024		Clare Joy

Section C Notes to the Accounts

C1 Restricted funds CSF Links Fund - to provide mental health support KB/Rregistry Fund - To set up and run a CSF leak patient registry

	Type of activity or project supported	Individual / institution
C2 Grants	None	

C3a Trustee No remuneration was paid during the period to any charity trustee or person connected to a trustee

Authority under which paid

C3b Trustee remuneration - details None

C4a Trustee expenses Total epenses during the period

C4b Trustee expenses - details Hotel & registration 3 day BASH conference Hull Jan 2025 to raise awareness note travel expenses not claimed

	Nature of relationship	Nature of transaction
C5 Transactions with trustees and connected persons	None	

Notes:

The bank balance 2024/25 is sufficient for operational costs. Income increased due to focused efforts on fundraising and contributions from Integra for DuraGenius game. The remaining income was from donations, memebership and small commission on sales of branded goods a bank interest. Funds designated for future research projects.

A restricted grant to fund the registry was received from The Miss Margret Butters Reekie Trust

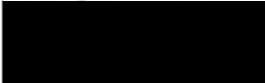
Expenditure relates to fundraising activities and charitable activities. Direct insurance and using Teams for meetings reduced costs. The cost savings enacted in previous years enables a greater investment in digital to improve efficiency and security.

We continue to work towards our aims as set out in the constitution. Publicising the guidelines published in May 2023 is leading to more people being diagnosed and receiving treatment reducing suffering and harm and reducing the burden of undiagnosed patients on society.

Sufficient reserves are maintained to meet the reserves policy of 6-9 months budgeted operational costs for the year.

APPENDIX 3



Independent examiner's report on the accounts														
Report to the trustees/members of	Charity name CSF Leak Association													
Registered charity number	SC046319													
On the accounts of the charity for the period	Period start date													
	<table border="1"> <thead> <tr> <th>Day</th> <th>Month</th> <th>Year</th> <th>to</th> <th>Day</th> <th>Month</th> <th>Year</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>4</td> <td>2024</td> <td></td> <td>31</td> <td>3</td> <td>2025</td> </tr> </tbody> </table>	Day	Month	Year	to	Day	Month	Year	1	4	2024		31	3
Day	Month	Year	to	Day	Month	Year								
1	4	2024		31	3	2025								
Set out on pages	1-3													
Respective responsibilities of trustees and examiner	The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) 2005 Act and the Charities Accounts (Scotland) Regulations 2006 (as amended). The charity trustees consider that the audit requirement of Regulation 10(1) (d) of the Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act and to state whether particular matters have come to my attention.													
Basis of independent examiner's statement	My examination is carried out in accordance with Regulation 11 of the 2006 Accounts Regulations. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeks explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and, consequently, I do not express an audit opinion on the view given by the accounts.													
Independent examiner's statement	In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*] 1. which gives me reasonable cause to believe that in any material respect the requirements: <ul style="list-style-type: none"> to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations have not been met, or 2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.													
Signed:	 Date: 16th June 2025													
Name:	Alasdair Lawton													
Relevant professional qualification(s) or body (if any):	ICAEW Membership Number 7766919													
Address:	2 Ardival East Strathpeffer Highland IV14 9DY													

*Please delete the words in the brackets if they do not apply. If the words do apply, set out those matters which have come to your attention on the following page.

Disclosure section

Only complete if the examiner needs to highlight material problems.

**Give here brief details of
any items that the
examiner wishes to
disclose**

A large, empty rectangular box with a thin black border, intended for the user to provide details of items to be disclosed. The box is currently blank.

Thank You



Together we make a difference

Thank you to our members, volunteers, fundraisers, supporters, advisors, trustees and donors for continuing your support

Cerebrospinal Fluid Leak Association

