



**Cerebrospinal Fluid Leak  
Association Trustees' Annual  
Report  
and  
Financial Statements  
for  
Year End 31 March 2024**

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## Legal and Administrative Information

Charity Registration Number	SC046319
Registration Date	5 <sup>th</sup> February 2016
Registered address	Unit 110982 PO Box 26965 Glasgow G1 9BW
E-mail	<a href="mailto:office@csfleak.uk">office@csfleak.uk</a>
Independent Examiner	Alasdair Lawton
ICAEW Membership Number	7766919

# Cerebrospinal Fluid Leak Association

## Trustees' Report For The Year Ended 31 March 2024

The Trustees present their report and accounts for the period ended 31 March 2024.

*Our vision is a world where every person with CSF leak symptoms is listened to and where every CSF leak is recognised, located, and fixed in a timely manner*

### Objectives and Activities

The CSF Leak Association was set up in response to the complete lack of awareness, information and support available to CSF leak sufferers, their families and friends. Patients have experienced a denial of healthcare, due to a lack of awareness about the condition amongst the medical profession and high levels of variation in access to specialised care, diagnostic tests and treatment options. Our primary objective is to improve healthcare provision for every person with CSF leak symptoms; to enable quicker diagnosis and treatment so that the probability of successful outcomes from treatment is increased and patient suffering is reduced. In founding the charity, we recognised we would need to foster good relationships with those members of the medical profession providing services to CSF leak patients despite the general lack of awareness, support and diagnostic or treatment pathways.

The CSF Leak Association's aims and objectives, as set out our constitution, are:

1. To raise the profile and promote awareness of Cerebrospinal Fluid Leaks (with a particular focus on spinal Cerebrospinal Fluid Leaks), hereafter within these purposes referred to as 'CSF Leaks', in all areas of society, including the general public, the media and the medical profession, for the public benefit;
2. To improve, for the public benefit, the general availability of and access to information and resources relating to the causes, symptoms, diagnosis and treatment of CSF Leaks;
3. To advance, for the public benefit, understanding of the causes, symptoms, diagnosis and treatment of CSF Leaks through research, education, fora, publications, practical advice, and other appropriate means and services;
4. To campaign for, encourage and support positive change and advancements within government, the four national health services within the UK, other relevant health care providers (including those out with the UK), other relevant organisations and general society that address the various issues faced by people suffering or suspected to be suffering from CSF Leaks, their families and supporters;

5. To work to support and improve the availability of and access to investigatory tests and treatments required by people suffering or suspected to be suffering from CSF Leaks;
6. To encourage and support the establishment, development and furtherance of organisations and initiatives the aim(s) of which are to a) undertake and/or facilitate research into CSF Leaks (incl. their underlying causes and resultant effects) and/or b) support people suffering or suspected to be suffering from CSF Leaks, their families and supporters;
7. The promotion of such other similar charitable purposes as may from time to time be determined.

The main activities of the charity pursuant to these objectives include:

- Facilitating collaboration and organising meetings between patients and clinicians to improve healthcare provision for people with CSF Leaks.
- Provide up to date trustworthy information and support to people with, affected by, or involved with the diagnosis, treatment and management of CSF Leaks;
- Linking members with each other for mutual support and exchange of ideas;
- Publishing factsheet and posters;
- Supporting research projects that will benefit those with CSF Leaks;
- Producing a newsletter Leaker Life;
- Maintaining a website and social media presence to promote public awareness and provide support;
- Online support and information

The trustees have paid due regard to guidance issued by OSCR in deciding what activities the charity should undertake.

## **Achievements and Performance**

Areas of strategic focus are:

1. Improve healthcare provision
2. Facilitate research
3. Educate & Increase awareness
4. Patient Support
5. Optimising our website with a focus on security, resiliency, and maintainability
6. Increase fundraising for a patient registry

A summary of our activities is provided under these headings.

# 1. Improving Healthcare Provision

## 1.1. Publishing Guidelines

It is with great pride that we report that the guideline manuscript '[Multidisciplinary consensus guideline for the diagnosis and management of spontaneous intracranial hypotension](#)' was accepted by the BMJ Journal of Neurology Neurosurgery and Psychiatry in early 2023 and it was published in the May 2023 edition. The guideline was the result of nearly three years hard work by a multidisciplinary SIH Special Interest Group (SIG) which included patient members. The guideline was written with the intention of directly influencing clinical practice, increasing the consistency of care, improving diagnostic accuracy, and promoting effective investigations and treatments.

It includes 22 of the most clinically relevant questions covering all aspects of the patient pathway from patients first accessing care after symptom onset, diagnostic tests, interventions, treatments to follow up. Crucially it presents treatment algorithms for both MRI-positive and MRI-negative patients. In addition to the 9-page journal article three items of supplementary material were made available. Item 1 is a longer document with more detail about the consensus levels reached for each statement (>70% required for inclusion into guideline), the grade of the evidence supporting the statement (A being high quality and D being very low quality) and the evidence base including discussion about areas of uncertainty. Items 2 & 3 are a quality standard and audit tool respectively and are intended to be used for the auditing and monitoring of guideline implementation in a real clinical environment.

The final manuscript benefited from invaluable feedback and insight provided by a number of internationally renowned CSF leak experts, members of the public, patients and professional bodies including the Association of British Neurologists Headache and Pain Advisory Group, the British Association for the Study of Headache, the Royal College of Physicians, the Royal College of Physicians of Edinburgh, the Royal College of Anaesthetists, the Association of Anaesthetists, and the Obstetric Anaesthetists Association.

We were delighted that a number of professional bodies including The Royal College of Physicians, Association of British Neurologists and Royal College of General Practitioners endorsed the guidelines and it is hoped that this will mean the guidelines will be seen and accepted by more healthcare professionals. We remain committed to providing centres of excellence in the nations and regions and view the guidelines as a crucial first step in this endeavour.

We extend special thanks to the doctors and volunteers for their time and expertise in helping to produce the guidelines, especially Prof Matharu and Dr Cheema for the many hours they have spent on this our most important endeavour. We are forever indebted to the patients who gave up their time and ensured the patients voice and experience was heard and kept central to the SIG's work and to the large number of people who took the time to provide valuable feedback on the draft text some months before publication.

## 1.2. Promoting the Guidelines

We are especially proud of the fact that, with our financial support, the guideline was published as open access and as such it is freely available for downloading, printing and sharing without restriction worldwide. For ease of access the guidelines are hosted in full with the supplemental materials on a new webpage within our website:

[csfleak.uk/medical-guidelines](https://csfleak.uk/medical-guidelines). (Also present on our website are published guidelines from research groups not affiliated with the CSFLA related to post dural puncture headache and spontaneous CSF rhinorrhoea.)

## 1.3. International CSF Loss Expert Meeting Freiburg

In March/April 2023 we began working on raising awareness of the guidelines' existence before the guidelines were published. Prof Matharu was invited to present them at the International CSF Loss Expert Meeting held in Freiburg Germany in collaboration with the Bern group in Switzerland. Our chair, Clare Joy, who was also in attendance, reported that the presentation was very well received by the audience with many sincere compliments on the thoroughness of the work and how incredibly useful it was to have guidelines of such quality available to doctors and patients worldwide. Extremely fruitful discussions ensued and multiple contacts were made with clinicians across Europe and North America who were all grappling with similar diagnostic and therapeutic challenges. It was extremely heartening to know that so many talented doctors are motivated to learn and understand more about a condition that so often proves challenging in the face of so much that is yet to be researched and understood.

We are pleased to report that from publication up until 31st March 2024, the guidelines were cited by other research articles 17 times and downloaded over 20,000 times. The journal article is rated as having a 'High Attention Score' compared to articles of the same age, being in the top 5% of all research articles scored by Altmetric, a data science company that tracks where articles are mentioned online (for further information please visit <https://bmj.altmetric.com/details/147627645>).

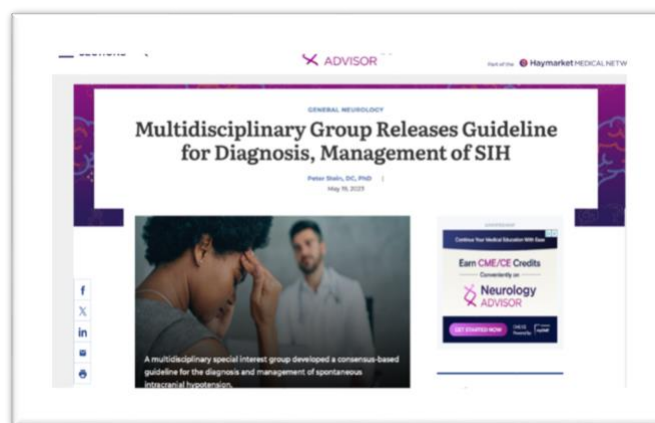


Figure 1 - Neurology Advisor article on the guidelines being published

In May 2024 the guidelines were selected for a feature article by Neurology Advisor, a digital media outlet aimed at neurology healthcare professionals wishing to keep their knowledge up to date. The article may be read at

<https://www.neurologyadvisor.com/topics/general-neurology/multidisciplinary-group-releases-guideline-diagnosis-management-sih/>

We continue to work with professional bodies to publicise the guidelines and encouraged the authors to present them at national and international conferences.

### **1.3. Presentation to Welsh Neurology Academic meeting**

Trustee Dr Bern Hard was invited by Dr Joe Anderson, her neurologist at Aneurin Bevan University Health Board. to talk to the neurologists, neuroradiologist and neurosurgeons at the monthly academic meeting. The topic was on the presentation and management of Spontaneous Intracranial Hypotension, and she used her story from presentation in October 2022, through MRI and CTM, to surgical repair in August 2023, and post operative MRI showing resolution in November 2023. Mr Parag Sayal (Consultant Neurosurgeon & Clinical Lead for Complex spine surgery & Endoscopic skull base surgery at The National Hospital for Neurology & Neurosurgery, London) attended the meeting virtually and co-presented.

The meeting was well attended by many consultants and specialist trainee doctors, who found the question answer session at the end particularly helpful. Mr Sayal provided guidance as to the role of a CSF leak multidisciplinary team (MDT) approach to managing patient care.

Dr Bern Hard has been invited back to present at a future training day which will include CSF disorders for Neurology Specialist Registrars.

### **1.4. Membership of The Neurological Alliance**



In September 2022 the charity became a member of The Neurological Alliance (TNA). We continue to support the TNA's #BackThe1in6 campaign bringing awareness of the fact that although 1 in 6 people live with a neurological condition there simply isn't the workforce or services in place to support them.

During the course of the year trustees attended Policy Sub-group and Rare Disease Sub-group meetings and found them to be useful networking opportunities as well as providing a united mechanism for dialogue with policymakers in the NHS. Further information about the work of TNA is available from their website (<https://www.neural.org.uk>).

### **1.5. Additional activities**

We are a member of Genetic Alliance UK, working together with other rare disease groups to improve the lives of people in the UK with genetic, rare and undiagnosed conditions. We participate in Rare Disease UK a long-standing and pioneering national campaign that represents and unites everyone in the rare disease community.

We are supporters of Cambridge Rare Disease Research Network an initiative set up this year by CamRare which aims to facilitate rare disease patient groups access to research.

We are proud to have participated in Medics 4 Rare Diseases red flag survey to highlight the common problems faced by rare diseases patients, the results are being analysed this year and are due for publication in 2024.

*"I would probably still be at my worst health wise, abandoned by my hospital, if it wasn't for the dedicated work from volunteers of the CSF leak association, and I'm so incredibly grateful for the advice and support I had at the time"*

## **2. Facilitating research into SIH**

### **2.1. Healthcare professionals and patient surveys**

Our original research survey of healthcare professionals, '[Knowledge, attitudes and practices regarding spontaneous intracranial hypotension](#)' published in September 2022, continues to promote awareness and education about SIH among non-specialist healthcare professionals. The publication is currently ranked in the top 25% of all research outputs tracked by Altmetric and with a High Attention Score in the 92nd percentile compared to outputs of the same age.

Our original research survey of patient experience, '[Patient experience of diagnosis and management of spontaneous intracranial hypotension: a cross-sectional online survey](#)' published in January 2022, similarly continues to promote awareness about the impact of SIH on patients. The publication is currently ranked in the top 5% of all research outputs tracked by Altmetric and with a High Attention Score in the 95<sup>th</sup> percentile compared to outputs of the same age. From publication until 31<sup>st</sup> of March 2024 it has been cited 11 times.

### **2.2. Orthostatic headache**

As strange as it might sound there is no one definition for the most common symptom of SIH, an orthostatic headache. Defining this symptom in a robust fashion so that it can reliably be used in a clinic setting is necessary to reduce the risk of misdiagnosis and ineffective treatments. A definition could also be used in future research which would make it easier to draw comparisons between the results of different research groups worldwide. We have been working with a group of neurologists from the SIG to define this symptom based on real world symptoms reported by patients with SIH.

### **2.3. Patient Registry**

Working through the guideline development process made it painfully obvious how little is understood about how CSF leaks develop, their natural history, the best treatments, in what time frame or the consequences of living with a leak for a prolonged period of time. Work is well underway with our partners in UCL and a clinical systems software company towards the establishment of an CSF Leak registry. It is intended that the registry, once fully tested and compliant with UK GDPR regulations, will be available across the UK using a web-based platform. Both a medical professional portal and a patient portal are planned. The eligibility criteria, once agreed through an ethics process, are intended to include adults who have any type of spinal CSF leak however there will be tight exclusion

criteria to ensure only high quality data may be used for later anonymised extraction for use in research.

Patients participating in the registry will be expected to interact with the portal and complete various online forms aimed at tracking their symptoms and the effects their symptoms are having on their lives. Participation is to be expected for at least 5 years but hopefully longer so that data on the longer terms effects of having a CSF leak are obtained. Ultimately the continued operation and success of the registry will depend on meeting the initial and ongoing funding requirements.

We have worked hard with our partners to establish the minimum requirements of a registry including legal and technical aspects, identify a clinical systems partner, devise suitable governance procedures and explore sources of funding. We know that forming a registry will require massive effort and funds as well as willing participants and a team of volunteers but we look forward to the challenges ahead.

### 3. Education and Awareness

During this reporting period, we used social media to highlight fundraising and awareness events. Online workshops run by other charities helped build skills in creating short videos for social media platforms, and how to use choose the right platform for different audiences and different purposes. Our popular animated video '[An Introduction to Cerebrospinal Fluid Leaks](#)' has now been viewed an astonishing 97,159 times since it was published in 2017.

#### 3.1. Headache academy

We were delighted to be invited to attend the Headache Academy where we had a stand and interacted with many of the attendees. The two-day event saw neurologists, GPs and headache nurses attend a series of lectures about the wide range of headache conditions. The guidelines were presented by Prof Manjit Matharu and our chair had an opportunity to speak to the audience about the importance of adopting the guidelines into clinical practice and how much it would affect patient's lives.



Figure 2 - Proud to have the charity logo up on screen alongside international experts.

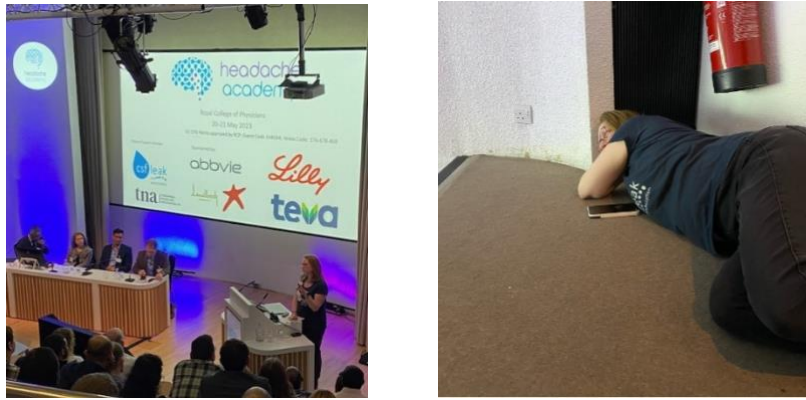


Figure 3 – (Left) Chair Clare Joy presenting the impact of the guideline for SIH from the patient perspective to clinicians at the Headache Academy and (Right) Chair Clare Joy having to lie down after the presentation - the reality of living with a CSF Leak

### 3.2. Partnership with Rare revolution

In September 2023 the charity became a member of Rare Revolution a charity raising awareness of rare diseases in society.



### 3.3. Leak Week

This year in the annual awareness event, Leak Week, we joined forces with the North American charities, Spinal CSF Leak Foundation (USA) and Spinal CSF Leak Canada to highlight the reality of life with a CSF Leak, having to lie flat; with the theme of 'a view from here'. People were asked to send in their view of the world from wherever they were at that time, and these images were collated to make a hard hitting video presentation which can be viewed here: [#theviewfromhere - living with a Spinal CSF Leak - YouTube](#).

This encouraged much discussion and interaction with our community and beyond. The global links with the other charities made the event 24/7 and the community of 'leakers' felt very connected. We used videos and written stories from patients to emphasise the human aspect of experiencing a CSF leak and updated our website with new patient stories, providing links to these. We also had some national buildings lit up for Leak Week which were promoted on their social media. 'The view from here' was a very successful campaign, and the global connection experienced by our community was far greater than we expected. We plan to work with both North American charities next year.



## 4. Patient Support

We are extremely thankful to Sandie who continues to respond with compassion and understanding to those who contact us via the website.

Providing specialist support has long been an ambition of the charity especially since the patient survey undertaken by the charity as part of the guideline work showed very clearly that this much neglected patient group were in need of mental health support. A grant from the National Lottery Scotland enabled a workshop, specialist support groups and counselling services for individuals and couples to help them navigate the difficulties of adjusting to the severe impact of having a CSF Leak. We partnered with Rareminds, an organisation who provide highly specialised counselling for the rare disease community and campaign for recognition of the importance of specialist mental health support by informing policy.

*“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.”*

CSF Leaks are psychologically challenging. Before the workshop there were high levels of anxiety, isolation and hopelessness. Afterwards the workshop was described as ‘vital’ with participants feeling ‘connected’, ‘validated’ and ‘heard’.

*“This has helped me enormously work through my emotions. Having the support has helped me look and plan for my future in a more positive way”.*

## 5. IT Optimisation and Improvements

Our website aims to inform, educate and raise awareness of CSF leaks and associated conditions. In our ongoing drive to streamline and modernise our IT infrastructure, we have successfully decommissioned our Membership Admin Portal. The reporting and functionality have been seamlessly integrated into our website by our agency Webdna. This strategic move has yielded several benefits:

1. Reduced operational overheads through the consolidation of IT systems
2. Establishment of a single, authoritative source for membership data
3. Enhanced overall security posture
4. Elimination of our reliance on hosting services provided by 34SP

These improvements not only simplify our IT estate but also pave the way for more efficient operations and improved data management.

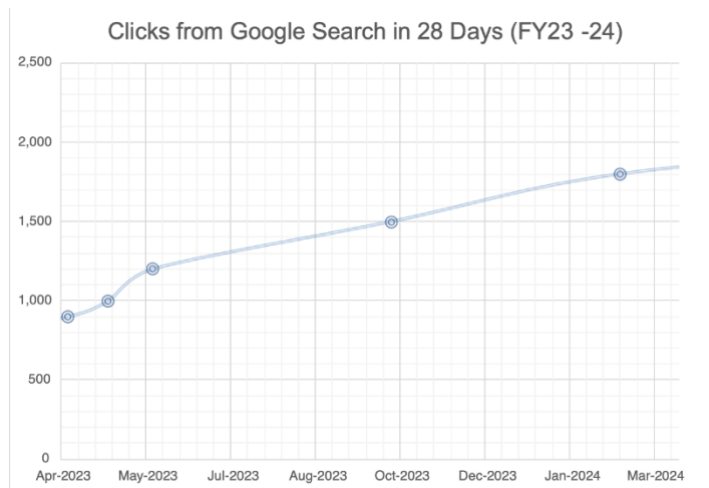


Figure 4 – Number of clicks from Google searches during the reporting period

*"I've been a "leaker" for a number of years and your website has always been an invaluable source of information and hope for me. I hope this donation helps you to continue the amazing work"*

## 6. Fundraising

In the financial year April 2023 to March 2024 at year end there was an unrestricted profit of £8,987 on an overall turnover of £26,665. We will continue to raise funds for specific projects from further grant applications. In order to carry out our activities it is vital sufficient funds are raised to support the CSF Leak community.

Income from fundraising this year increased significantly from the previous year with more focus and effort put into generating funds from more fundraising events, including those organised by individuals and by campaigns led by the charity. We are delighted to report that we received £9,850 awards for all grant from the National Lottery Scotland to fund a workshop, Support Groups and counselling service for people in Scotland with CSF Leaks. We are especially grateful to the National Lottery Scotland for their grant to help us develop online services to our community in Scotland to provide mental health support initiatives. We plan to apply for further funding to enable roll out of these services across the country.

### 6.1. Thank you to our fundraisers

We are overwhelmed by the incredible achievements of our amazing fundraisers who have supported the charity this year. Their dedication, generosity, and hard work have made a profound impact on the lives of countless individuals. Because of their efforts, we can continue to help people get the treatment they need to regain their health and end the torment of living with a CSF Leak.

Special thanks go to Jed a fantastic fundraiser who ran the Brighton half marathon this year and has an incredible challenge planned for 2024. Every donation and every fundraising effort helps us move closer to our aim of swift, effective treatment of all CSF leaks and we extend our heartfelt thank you to every fundraiser.

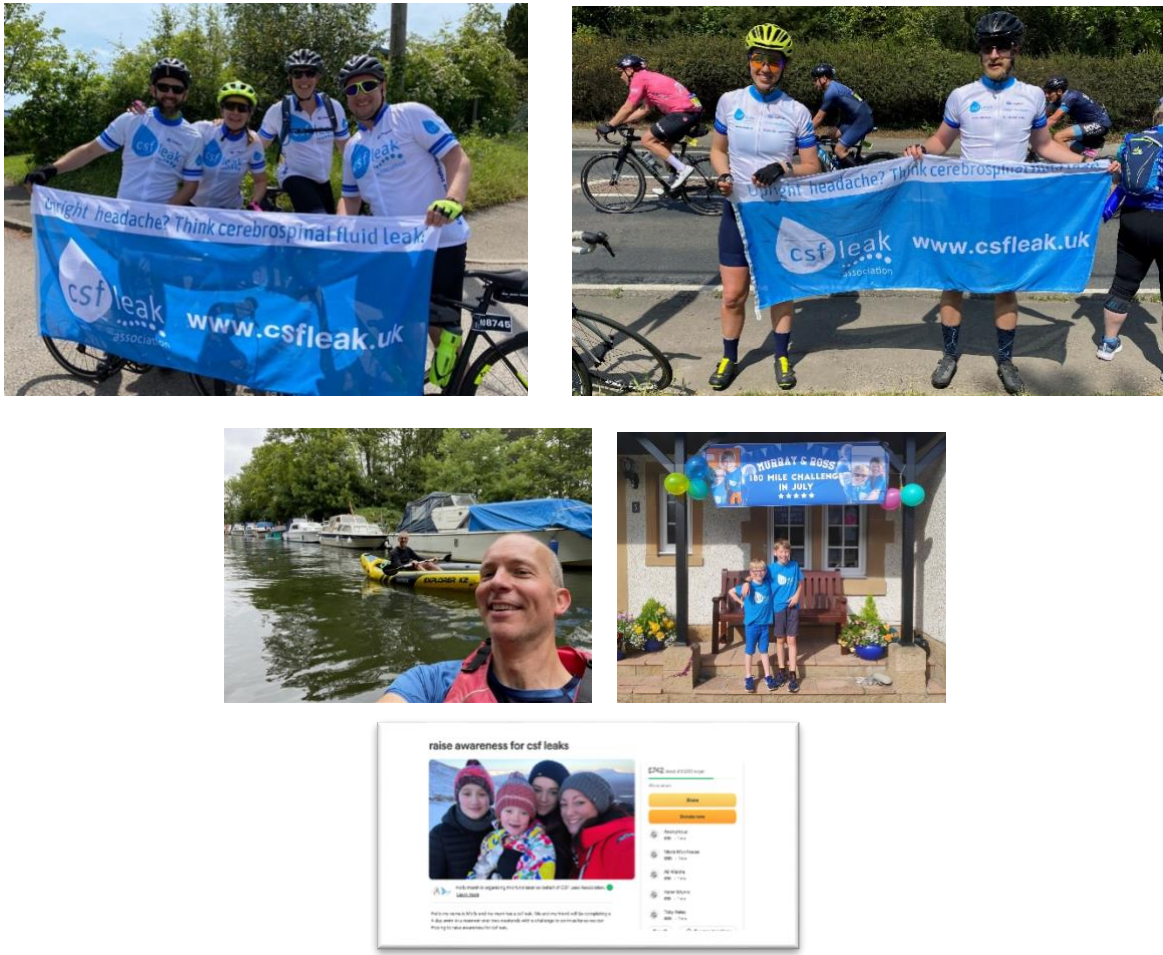


Figure 5 - Some of our talented fundraisers in action

## 6.2. Easyfundraising & Give as you live

These are free portals through which internet shopping is carried out. For each transaction made, a small percentage of money makes its way to the CSF Leak Association. There is no cost to the shopper, so it's an excellent way to generate donations without any cost to the buyer.

## 6.3. Don't Send Me A Card

With a donation to our charity, people are able to send up to 10 e-cards to others.

*"Our family has been affected by this severe and rare disease, advice from this charity has this helped us to understand how to fight it."*

## 7. Future Plans

### 1. Improve healthcare provision

We will continue to raise awareness of the guidelines and expect SIG members to present the guidelines to their respective professional communities. We also intend to advocate for the provision of CSF leak services across all four nations in the UK.

### 2. Facilitate research

We will continue working with our partners on the necessary foundation work to establish a national registry for patients with spinal CSF leaks. We also hope to see papers published on the definition of an orthostatic headache and managing SIH in pregnancy.

### 3. Educate & increase awareness

We will take any and all opportunities to raise awareness of CSF leaks with medical professionals and members of the public including collaboration with other charities where appropriate. We hope to run a series of webinars for patients in the coming year to improve health literacy and enable patients to get the most out of interactions with their GP and other doctors. We would like to work on producing a lay summary of the guidelines which is accessible to all patients.

### 4. Information technology

Looking ahead, our IT strategy will focus on several key areas:

- a. **Website Enhancement:** We plan to continually improve our website, with a particular focus on user experience. As part of this effort, we are evaluating the potential benefits of upgrading to the latest version of Craft CMS. This upgrade could offer improved performance, enhanced security features, and a more robust set of tools for content management.
- b. **Search Engine Optimisation (SEO):** We are dedicating resources to bolster our SEO efforts. This investment aims to increase our online visibility, drive more relevant traffic to our website, and ultimately enhance our reach within the CSF leak community.
- c. **IT Infrastructure:** Our commitment to excellence in IT continues with plans to further refine our IT estate. This includes:
  - i. Strengthening our cybersecurity measures to protect sensitive data
  - ii. Improving system resilience to ensure uninterrupted service
- d. **Data Analytics:** We aim to leverage data analytics tools to gain deeper insights into our members' needs and preferences, allowing us to tailor our services more effectively.
- e. **Accessibility:** We will prioritise digital accessibility to ensure our online resources are available to all, regardless of ability or assistive technology used.

### 5. Increase fundraising

The Board of Trustees will continue to widen the range of funders.

## **Thank You To Our Supporters**

The Board of Trustees want to take this opportunity to thank, fellow volunteers, our membership, members of our Medical Advisory Committee, members of the SIH special interest group and our supporters and the amazing fundraisers for all they have done in this reporting period. Generously giving their time and expertise to help us achieve the goals to which we continually strive.

## **Financial review**

Incoming resources for the year totalled £26,665 of which £11,389 related to funding for projects upon which restrictions are placed.

Total expenditure for the period was £17,678. The largest expenses were the cost of publishing the guideline manuscript £4,440, upgrading the website £4,881 and the lottery funded support services £6,785

At 31<sup>st</sup> March 2024 the charity's total funds stood at £68,476 of which £4,604 represented restricted funds.

We ensure that our reserves policy is sustainable and provides the required funds to maintain a secure website to provide up to date trustworthy information, continue working to improve healthcare, support patients and increase designated funds for future research into SIH and CSF Leaks.

## **Reserves Policy**

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to a minimum of 12 months operating expenditure. The trustees consider that reserves at this level will ensure that in the event of a significant drop in funding, they will be able to continue the charity's current activities whilst consideration is given to ways in which additional funds may be raised or the operating costs reduced. This level of reserves has been maintained throughout this period.

## **Principal Funding Source**

CSF Leak Association raises its funds through fundraising activities, grants and donations, members' subscriptions and through the sale of branded goods through its online shop.

## **Donated facilities and services**

We would like to thank the following people and companies for donating goods and services to our charity:

Independent examination by Alasdair Lawton  
M365 from Microsoft

All the clinicians and those with lived experience of CSF leaks for their time and expertise in the development of consensus guidelines.

Keeper Security for discounted password management software

## **Structure, governance and management**

The CSF Leak Association is a SCIO, Scottish Charitable Incorporated Organisation, governed by our constitution. Trustee meetings are held six times a year and agree all matters relating to the CSF Leak Association, it's broad strategy and areas of activity, including:

- The level of subscriptions payable by its members
- Annual income and expenditure budgets
- The allocation of its resources
- Risk management policies and performances

A Medical Advisory Committee covering the breadth of specialties which have contact with CSF leaks is maintained to provide the trustees with an expert view and to ensure that our advice and support is in line with current practice.

## **Data Protection & Privacy Policy**

We take privacy very seriously; we adhere to the principles of the UK General Data Protection Regulations and understands 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.

## **Equality & Equity Policy**

The CSF Leak Association is an equal opportunity charity taking into account the diversity within our community, members and volunteers.

We believe that everyone should be treated equally, regardless of their religion, beliefs, age, gender, race, disability or sexual orientation.

The Equality and Equity Policy requires commitment from everyone within the Charity. Our Chair, Clare Joy, is responsible for the implementation and effective operation of this policy.

## **Fundraising Promise**

This promise outlines the commitment made to our donors and the public when fundraising. We agree to ensure our fundraising is legal open, honest and respectful. We adhere to the standards for fundraising as set out in the Fundraising Regulator's Code of Fundraising Practice.

## Trustees

The Trustees are appointed in line with the provisions of the constitution. Membership of the Board is open to all members and elections are held at the AGM.

New Trustees are recruited by personal approach or recommendation by a current Trustee or when professional skills are required by advertising on social media. Candidate trustees are interviewed before appointment. New trustees are introduced to their new role and are given copies of the constitution and a guide to the policies and procedures adopted by our charity. A number of publications from OSCR are also provided. This ensures that new trustees are aware of the scope of their responsibilities under the charities Act.

CSF Leak Association maintains working relationships with other charities and umbrella organisations that share common purpose with the charity, none of these relationships amount to creating related parties.

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 the major risks. The charity is covered by £5,000,000 public liability and employers' liability insurance with Zurich Insurance.

## Trustees

<b>Name</b>	<b>Role (if any)</b>	<b>Dates active (if not for whole year)</b>
Clare Joy	Chair	
Shena Carrick		
Clare Sargeant	Treasurer	
Deborah Ogg		
Steve Hamilton		Retired 28 <sup>th</sup> February 2024
Adam Goldsmith	Secretary	
Bern Hard		Appointed 21 <sup>st</sup> June 2023
Khadija Ali		Appointed 21 <sup>st</sup> June 2023
Seetal Popat		Appointed 5 <sup>th</sup> December 2023

## Declaration

The Trustees' report was approved by the Board of Trustees on 9th July 2024.

Signed on behalf of the charity trustees:

A handwritten signature in black ink, appearing to read 'Clare Joy', is written on a light-colored rectangular background.

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Clare Joy, Chair of Trustees

Date: 26th July 2024

Statement of Financial Activity  
For  
1<sup>st</sup> April 2023 to 31<sup>st</sup> March 2024



CSF Leak Association

SC046319

## Receipts and payments accounts

For the period

01 April 2023 - 31 March 2024

## Section A Statement of receipts and payments

	Unrestricted funds	Designated Funds	Restricted funds	Total funds	Total funds
				This YE 31/3/24	Last YE 31/3/23
	to nearest £	to nearest £	to nearest £	to nearest £	to nearest £
<b>A1 Receipts</b>					
Donations	64	-	1,539	1,603	9,851
Grants	-	-	9,850	9,850	2,000
Receipts from fundraising activities	11,327	-	-	11,327	10,999
Gross trading receipts	33	-	-	33	100
Gross receipts from memberships	1,985	-	-	1,985	1,525
Gift aid	-	-	-	-	841
Bank interest	1,867	-	-	1,867	138
<b>A1 Sub total</b>	<b>15,276</b>	<b>-</b>	<b>11,389</b>	<b>26,665</b>	<b>25,454</b>
<b>A2 Receipts from asset &amp;</b>					
From sale of investments & assets	-	-	-	-	-
<b>A2 Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>15,276</b>	<b>-</b>	<b>11,389</b>	<b>26,665</b>	<b>25,454</b>
<b>A3 Payments</b>					
Expenses for fundraising activities	201	-	-	201	1,950
Governance costs	-	-	-	-	-
Payments to charitable activities:					
Website & IT	4,881	-	-	4,881	2,146
Publish survey/guideline	4,440	-	-	4,440	-
Awareness and Admin	1,143	-	-	1,143	254
CSFLA Membership Costs	122	-	-	122	133
Insurance & PO box	106	-	-	106	96
CSF Links project	-	-	6,785	6,785	-
<b>A3 Sub total</b>	<b>10,893</b>	<b>-</b>	<b>6,785</b>	<b>17,678</b>	<b>4,579</b>
<b>A4 Payments relating to asset and</b>					
Purchases of tangible assets	-	-	-	-	-
Purchase of investments	-	-	-	-	-
<b>A4 Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>10,893</b>	<b>-</b>	<b>6,785</b>	<b>17,678</b>	<b>4,579</b>
<b>Net receipts / (payments)</b>	<b>4,383</b>	<b>0</b>	<b>4,604</b>	<b>8,987</b>	<b>20,875</b>
<b>A5 Transfers to / (from) funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Surplus / (deficit) for year</b>	<b>4,383</b>	<b>0</b>	<b>4,604</b>	<b>8,987</b>	<b>20,875</b>

**Cerebrospinal Fluid Leak Association**


**SC046319**

**Receipts and payments accounts**

**Section B Statement c**

	Unrestricted funds	Designated funds	Restricted funds CSF Links	Restricted funds KB	Total YE 31/3/24	Total YE 31/3/23
	nearest £	nearest £	nearest £		nearest £	nearest £
<b>B1 Cash funds</b>						
Balance at start of year	19,490	40,000	-	-	59,490	38,615
Surplus/(deficit) from receipts and payments account	4,383	-	3,065	1,539	8,987	20,875
Movement in funds	(10,000)	10,000	-	-	-	-
<b>Cash and bank balances at end of year</b>	<b>13,873</b>	<b>50,000</b>	<b>3,065</b>	<b>1,539</b>	<b>68,477</b>	<b>59,490</b>

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

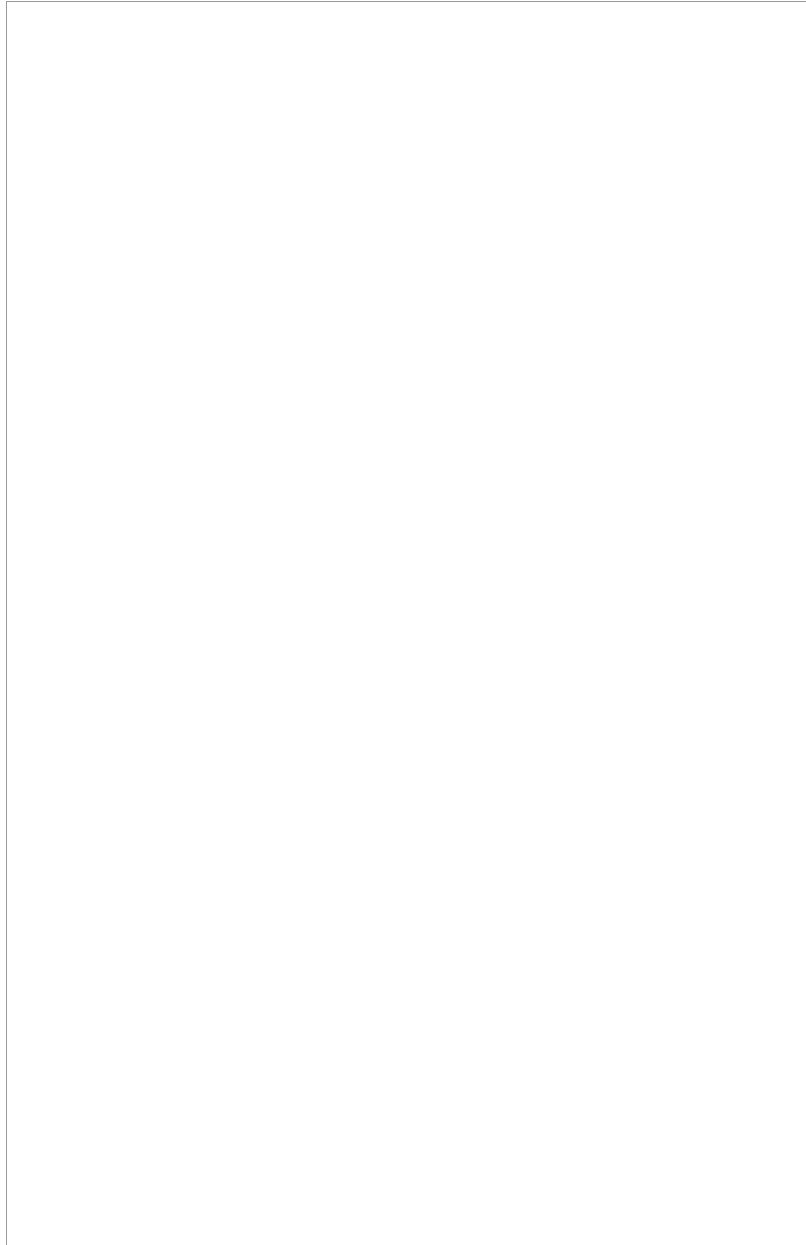
Approved D	Signature	Print Name
21/06/2024		Clare Joy



**APPENDIX 3**

		<b>Independent examiner's report on the accounts</b> v2					
<b>Report to the trustees/members of</b>	Charity name	<b>CSF Leak Association</b>					
	Registered charity number	<b>SC046319</b>					
<b>On the accounts of the charity for the period</b>	Period start date				Period end date		
	Day	Month	Year		Day	Month	Year
	<b>1</b>	<b>4</b>	<b>2023</b>	<b>to</b>	<b>31</b>	<b>3</b>	<b>2024</b>
<b>Set out on pages</b>	1-3					(remember to include the page numbers of additional sheets)	
<b>Respective responsibilities of trustees and examiner</b>	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.						
<b>Basis of independent examiner's statement</b>	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.						
<b>Independent examiner's statement</b>	<p>In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]</p> <p>1. which gives me reasonable cause to believe that in any material respect the requirements:</p> <ul style="list-style-type: none"> <li>• to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and</li> <li>• to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations</li> </ul> <p>have not been met, or</p> <p>2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.</p>						
<b>Signed:</b>				<b>Date:</b>	25 <sup>th</sup> June 2024		
<b>Name:</b>	Alasdair Lawton						
<b>Relevant professional qualification(s) or body (if any):</b>	ICAEW Membership Number 7766919						
<b>Address:</b>	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.





# Thank You

To our members, volunteers, fundraisers, supporters,  
advisors, trustees and doners for continuing your support of  
the

Cerebrospinal Fluid Leak Association