CSF Leak Association

Trustees' Annual Report

Year End 31 March 2023

Legal and Administrative Information

Charity Registration Number	SC046319
Registration Date	5th February 2016
Registered address	Unit 110982 PO Box 26965 Glasgow G1 9BW
E-mail	office@csfleak.info
Independent Examiner	Alasdair Lawton
ICAEW Membership Number	7766919

CSF Leak Association

Trustees' Report For The Year Ended 31 March 2023

The Trustees present their report and accounts for the period ended 31 March 2023.

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. Optimising our website with a focus on security, resiliency, and maintainability
5. Increase fundraising

A summary of our activities is provided under these headings.

1. Improving Healthcare Provision

a. Guidelines

In July 2022 we were delighted to put out for public consultation a draft version of the guideline the SIH Special Interest Group (SIG) had worked so hard and so long on. We also arranged for the draft to be submitted to a number of well respected international experts and a host of professional bodies. Each comment was addressed and those that

could not be easily addressed were brought to a virtual meeting where changes to the guideline statements were discussed and voted upon. All the feedback was incredibly useful in refining the final manuscript for later submission for publication to the Journal of Neurology, Neurosurgery & Psychiatry in January 2023.

It is with great pride that we report that a number of professional bodies including The Royal College of Physicians, Association of British Neurologists and Royal College of General Practitioners have agreed to endorse the guidelines. 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 an important first step. We look forward to working on raising awareness of the guidelines' existence with our Medical Advisory Committee. In fact, before the guidelines were published Prof Matharu was invited to speak in March 2023 at the International CSF Loss Expert Meeting held in Freiburg in collaboration with the Bern group. Our chair, Clare Joy, was also in attendance and reported that the presentation was very well received by the audience with lots of compliments about how thorough the work was and how useful it was.

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.

b. Membership of The Neurological Alliance

In September 2022 the charity became a member of The Neurological Alliance (TNA). We supported the TNA's #BackThe1in6 campaign bringing awareness of the fact that although 1 in 6 people live with a neurological condition but there simply isn't the workforce or services in place to support them. We support the petition calling on all UK governments to work together to create a UK-wide Neuro Taskforce to improve services for people affected by neurological conditions. 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/)

c. Rareminds

The charity investigated options to improve the provision of mental health services to sufferers of CSF leaks and their families. We began discussions with Rareminds, a community interest company who provide affordable highly specialised counselling for the rare disease community. They also campaign for recognition of the importance of specialist mental health support by informing policy.

2. Facilitating research into SIH

As part of the guideline development process the Special Interest Group & the charity commissioned a survey of healthcare professionals' knowledge, attitudes and practices regarding spontaneous intracranial hypotension. This was published in BMJ Neurology

Open in September 2022. The paper can be read by visiting this link: https://neurologyopen.bmj.com/content/4/2/e000347

It was aimed at GPs, Emergency Department (ED) doctors, neurologists, radiologists, neurosurgeons, anaesthetists & headache nurse specialists. The results of the survey were unsurprising:

- Few GPs and ED doctors reported they felt confident recognising the symptoms of SIH.
- Most neurologists reported they felt confident in diagnosing SIH but there was variability in what imaging studies they would order as a result.
- Most neuroradiologists felt confident they would be able to identify the signs of SIH but only few general radiologists felt the same.
- Barriers thought to prevent adequate treatment included lack of access to epidural blood patching, myleograms performed by neuroradiologist and a lack of management guidelines.

These questions had never been asked before nor were there previous published surveys of this kind. It nicely underlined the need for the guidelines for patients but also for healthcare professionals. We wish to thank all members of the SIH SIG and charity volunteers who contributed their time in the development and testing of the questionnaire. For their impressive effort in carrying out the work and writing the paper, special thanks go to the authors Dr Sanjay Cheema (Clinical Research Fellow, UCL), Dr Jane Anderson (Consultant Neurologist, Addenbrookes), Dr Callum Duncan (Consultant Neurologist, NHS Grampian), Dr Indran Davagnanam (Consultant Neuroradiologist, NHNN), Dr Paul Armstrong (Consultant Neuroradiologist, Greater Glasgow & Clyde), Dr Nancy Redfern (Consultant Anaesthetist, RVI Newcastle), Anthony Ordman (Consultant in Pain Medicine), Linda D'Antona (Neurosurgeon, NHNN), Mr Justin Nissen (Consultant Neurosurgeon, RVI Newcastle), Mr Parag Sayal (Consultant Neurosurgeon, NHNN), Dr Eyston Vaughan-Huxley (Consultant Emergency Physician, Kings College Hospital), Susie Lagrata (Headache Nurse Specialist, NHNN), Dr Valeria Iodice (Consultant Neurologist, NHNN) Jessica Snape-Burns (Volunteer, CSFLA) Clare Joy (Chair, CSFLA) and Prof Manjit Matharu (Professor of Neurology, UCL and Honorary Consultant Neurologist, NHNN).

Working through the guideline development process has 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. We are excited to report that we have been in continued discussions with our partners in UCL & a clinical systems software company about the founding of an SIH registry. It is our fervent hope that this will help answer some of these questions; however, forming a registry will require massive effort and will require funds as well as willing participants.

"Thank you for everything you do. I have a potential CSF leak. It's currently undiagnosed and has become a battle to be heard. This association is a beacon of hope for a brighter future."

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.

a. RideLondon-Essex100

We promoted a team of four cyclists raising awareness and funds for us by introducing each person and reporting on their training for the 100 miles ride through central London and Essex. They wore charity cycling tops and arranged for banners and flags to be shown along the route.

b. Leak Week

This year was the first time since 2018 we were able to take part in the annual awareness event, Leek Week. We joined forces with the North American charities, Spinal CSF Leak Foundation (USA) and Spinal CSF Leak Canada to highlight some of the myths surrounding CSF leaks. Each day a statement was posted on social media, and questioned whether it was 'Fact or Fiction'. Later in the day, the answer would be posted, confirming that it was either a fact or fiction. This encouraged much discussion and interaction with our community. It also helped dispel some of the outdated thoughts about CSF leaks and allowed us to share the most up to date information and research. The global links with the other charities made the event 24/7 and the community of 'leakers' felt very connected. Our charity covered a different type of CSF leak each day. 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. 'Fact or Fiction' 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.

c. The Great North Run

We had one runner raising funds and awareness this year. Places are incredibly difficult to get, so we were very appreciative. We provided a vest with charity logos and promoted the fundraising links for donations.

d. Don't Send Me A Card

With a donation to our charity, people are able to send up to 10 e-cards to others. We added new designs to our Christmas selection and promoted the new 'share via WhatsApp' feature.

"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."

4. Optimising website

We have migrated the hosting of our Craft CMS website from 34SP to Servd (optimised Craft CMS hosting) managed by our new agency Webdna. The new hosting went live on

9th March 2023, and was subsequently followed by a significant version upgrade to Craft CMS and plug-ins helping to continue to maintain our security posture, optimise and improve the user experience. We continue to work with our Search Engine Optimisation (SEO) volunteer on increasing traffic to the website, determining new content to be built, and better serve our members.

A successful migration from Google Workspace to Microsoft 365 was executed, at the same time performing essential maintenance and review of accounts and access. We currently still need to maintain a limited set of users on Google Workspace but hope to decommission this in the near future. Moving to Microsoft 365 has allowed us to consolidate some IT services and improve charity collaboration through the use of Teams.

We took the decision this year to move from physical membership packs to digital membership packs. There were several reasons for this, the increasing cost of postage and print materials, specifically for international members, was reducing the ability to invest membership fees into charity initiatives, bulk printing and sending of materials was not sustainable and environmentally friendly. Much of the material had our previous website URL and branding and generally outdated. We worked with our graphic design volunteer to create or update materials and make them available in a fully digital format for members to access

"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"

5. Fundraising

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 had a year end unrestricted profit of £20,874 on an overall turnover of £25,454. We have been encouraged by a successful grant application for our new website and plan to continue to help 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.

We are incredibly grateful to our fundraisers and donors for their efforts over this challenging year enabling us to continue our work throughout the year.

We are especially grateful to the Hospital Saturday Fund for their grant to help us develop our online services to our community.

"Thank you for all that you do 💙"

Future Plans

1. Improve healthcare provision

The guideline manuscript will be accepted for publication and we will work to publicise them by working with professional bodies and encouraging authors to present them at

conferences. As they will be published as open access we will be able to host them on our website.

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.

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.

4. Information technology

The final stage of our IT optimisation is to migrate the functionality and reports from the Membership Admin Portal into Craft CMS. This will enable us to manage all membership functionality through Craft CMS, reducing the overhead of maintaining multiple systems, reducing security risks, and remove single point of failures in our IT systems. We will also be able to fully decommission Google Workspace and remove all hosting requirements from 34SP.

We will continue to focus on website SEO, with the intended benefit of increasing the number of members. We will look to develop more member only content and functionality and identify opportunities to engage the community.

5. Increase fundraising

The Board of Trustees will continue to widen the range of funders including targeting grant providers.

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 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 £25,454 of which £2,000 related to funding for projects upon which restrictions are placed.

Total expenditure for the period was £4,580.

At 31st March 2023 the charity's total funds stood at £59,489 of which none 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:

Hosting by 34SP
Independent examination by Alasdair Lawton
MS365 from Microsoft
Google workstation from Google
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
Adam Goldsmith for laptop

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 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.

Our 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

Name	Role (if any)	Dates active (if not for whole year)
Clare Joy	Chair	
Shena Carrick	Secretary	
Clare Sargeant	Treasurer	
Deborah Ogg		
Steve Hamilton		
Adam Goldsmith		Appointed 8th Feb 2023
Bern Hard		Appointed 21st June 2023
Khadija Ali		Appointed 21st June 2023

Declaration

The Trustees' report was approved by the Board of Trustees on 26th September 2023.

Signed on behalf of the charity trustees:

[redacted]

Clare Joy, Chair of Trustees

Date: 26th September 2023

APPENDIX 2

CSF Leak Association **SC046319**

Receipts and payments accounts

For the period 01 April 2022 - 31 March 2023

Section A Statement of receipts and payments

	Unrestricted funds	Designated Funds	Restricted funds	Total funds This YE 31/3/23	Total funds Last YE 31/3/22
A1 Receipts	to nearest £	to nearest £	to nearest £	to nearest £	to nearest £
Donations	3,851	6,000	-	9,851	2,398
Grants & Legacies	-	-	2,000	2,000	-
Receipts from fundraising activities	999	10,000	-	10,999	240
Gross trading receipts	100	-	-	100	28
Gross receipts from memberships	1,525	-	-	1,525	1,474
Gift aid	841	-	-	841	254
Bank interest	138	-	-	138	-
A1 Sub total	7,454	16,000	2,000	25,454	4,394
A2 Receipts from asset &					
From sale of investments & assets	-	-	-	-	-
A2 Sub total	-	-	-	-	-
Total receipts	7,454	16,000	2,000	25,454	4,394
A3 Payments					
Expenses for fundraising activities	1,950	-	-	1,950	567
Governance costs	-	-	-	-	-
Payments to charitable activities:					
Website & IT	2,146	-	-	2,146	160
Publish survey	-	-	-	-	1,800
Conference & memberships	254	-	-	254	70
CSFLA Membership Costs	133	-	-	133	69
Insurance (PO box, zoom)	96	-	-	96	1,376
A3 Sub total	4,579	-	-	4,579	4,041
A4 Payments relating to asset and					
Purchases of tangible assets	-	-	-	-	-
Purchase of investments	-	-	-	-	-
A4 Sub total	-	-	-	-	-
Total payments	4,579	-	-	4,579	4,041
Net receipts / (payments)	2,875	16,000	2,000	20,875	353
A5 Transfers to / (from) funds	(2,311)	-	2,311	-	-
Surplus / (deficit) for year	564	16,000	4,311	20,875	353

APPENDIX 2

CSF Leak Association **SC046319**

Receipts and payments accounts

Section B Statement of balances

		Unrestricted funds	Designated funds	Restricted funds website	Total YE 31/3/23	Total YE 31/3/22
		nearest £	nearest £	nearest £	nearest £	nearest £
B1 Cash funds	Balance at start of year	42,926	-	(4,311)	38,615	47,391
	Surplus/(deficit) from receipts and payments account	564	16,000	4,311	20,875	(8,776)
	Movement in funds	(24,000)	24,000	-	-	-
	Cash and bank balances at end of year	19,490	40,000	-	59,490	38,615

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

Date of approval	Signature	Print Name
20/4/2023	[redacted]	Clare Joy

APPENDIX 2 CSF Leak Association SC046319

Section C Notes to the Accounts

C1 Restricted funds

Website Fund - to update the website

C2 Grants

Type of activity or project supported	Individual / institution	Number of grants made	£
None		0	
		Total	-

C3a Trustee

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

C3b Trustee remuneration - details

Authority under which paid	£
None	0
	0

C4a Trustee expenses

No expenses were paid to any charity trustee during the period	x

C4b Trustee expenses -

	Number of trustees	£
None	0	0

C5 Transactions with trustees and connected persons

Nature of relationship	Nature of transaction	Transaction	Balance
None		0	0
		0	0
		0	0
		0	0
		0	0

Notes:
The bank balance remains healthy in 2023/23. Income increased due to focus on increasing effort on fundraising and a a large individual donation. The remaing income was from donations, commission on sales of branded goods and bank interest. Surplus funds have been designated for future research projects.
A restricted grant to fund the website was received from Hospital Saturday fund.

Expenditure relates to fundraising activities and charitable activities. A move to a virtual PO box, digital membership packs, direct insurance and using Teams for meetings reduced costs. The cost savings enabled a greater investment in digital security and the purchase of 3 laptops to improve efficiency and security.

We continue to work towards our aims as set out in the constitution. With the guidelines submitted for publication a transformation in the healthcare of CSF Leak patients is anticipated.

Sufficient reserves are maintained to meet the reserves policy of 2 years costs at current activity.

APPENDIX 3

OSCR
Scottish Charity Regulator

Independent examiner's report on the accounts

v2

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: Day **1** Month **4** Year **2022** to Period end date: Day **31** Month **3** Year **2023**
Set out on pages	13-15 (remember to include the page numbers of additional sheets)

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:
   - 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: [redacted] **Date:** 26th June 2023

Name: Alasdair Lawton

Relevant professional qualification(s) or body (if any): ICAEW Membership Number 7766919

Address: [redacted]

*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.

APPENDIX 3

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	

Thank You

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

CSF Leak Association