



CSF LEAK ASSOCIATION

Annual Report 2021/22

This annual report has been prepared for the Annual General Meeting of the Cerebrospinal Fluid Leak Association (also known as the CSF Leak Association) to be held on **5th October 2022**. The report covers the accounting period from 1 April 2021 to 31 March 2022 plus an overview of forthcoming work, and is intended for consumption by the membership. It was approved by the Board on **14th September 2022**.

Annual Report from the Trustees

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.

1. Introduction

The CSF Leak Association is now into its seventh year as a registered charity. It was set up in response to the complete lack of awareness, information and support available to CSF leak sufferers, their families and friends. The healthcare experience of many CSF leak sufferers was, and still is, less than satisfactory due to high levels of variation in access to specialised care, diagnostic tests and treatment options. In founding the charity, we recognised that we would need to foster good relationships with those members of the medical profession providing services to Leakers despite the general lack of awareness and diagnostic or treatment pathways.

The reporting period was another challenging year for our volunteers and members with Covid-19 still present and many being affected by disruption to their lives and healthcare services. The charity is run solely by volunteers, many of whom have direct experience of a CSF leak, with no paid staff. All current Trustees of the CSF Leak Association are fellow CSF Leakers or healed Leakers. Living life with a leak is a true test of patience, resilience and determination, to name just a few qualities, all of which are well suited to the demands of pursuing our aims and objectives.

This Annual Report seeks to set out our achievements in the reporting period. For those reading this, we hope this gives you an insight into the good work we have done and perhaps the inspiration to come and join us.

We want to take this opportunity to thank the Board of Trustees, 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 and for generously giving us their time. Each and every one of you has helped us towards our goals which we will continue to strive for at whatever pace we can.

2. Our charity's aims and objectives

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.

3. Governance and the Board of Trustees

The CSF Leak Association is governed by our constitution which was first adopted on 8 February 2016 and subsequently updated, most recently at the AGM on 19 November 2020. We have a range of policies adopted under the constitution on: accounting procedures, trustee code of conduct/conflict of interest, data protection, decision-making, email usage, equality & equity, expenses and publication of information.

The Board of Trustees currently consists of five people, all of whom are unpaid volunteers. Membership of the Board is open to all members and elections are normally held at the AGM meeting (although new trustees can still join the board during the year). Prospective trustees are required to complete an application form and be interviewed before being co-opted if successful. New trustees are offered induction training and encouraged to partake in ongoing or additional training as appropriate. We are always open to prospective trustees from outside our 'leaker' world and would welcome any person with a desire to help and a complementary skillset.

The Board manages the day-to-day running of the Association and meets formally via teleconference software. Most of our current Board, as well as the majority of our volunteers, currently suffer from CSF leaks or related health issues. This means that they have limited time upright due to the onset of symptoms whenever they sit up or stand. As a result, our work is structured and scheduled to what their health and other commitments allow. Meeting virtually so people can join in without having to leave their homes or even lie down if need be has been essential to the way we work. Our written resolutions mechanism allows certain decisions to be taken asynchronously out with a board meeting and this continues to work well especially if a trustee is unable to attend a meeting or events dictate a faster response is required.

The Board is assisted by a team of volunteers, some of whom have specific roles according to their skills and interest, e.g., Office Admin, Membership Admin, Policy & Governance, IT & Systems Admin, Social Media, Patient Representative. We use Google's G Suite business tool to organise and manage our work, including the use of instant messaging. Work is most often progressed through volunteer subgroups nominally led by a trustee, most of which support a specific stream of work while some are task and finish groups related to specific projects.

Appendix 1 details the charity trustees in office on the date of approval of this annual report along with details of other trustees who have been with us during the financial year.

4. How our work delivers our aims and objectives

As a Board, we continually reflect on the objectives set out in our constitution to ensure our activities fulfil these. We do this by way of our business plan which sets out core activities and enables us to monitor our progress. Each year we present this progress through our annual report to the membership at the annual general meeting. Based on our limited resources we prioritised the following key deliverables in the last reporting period:

- increasing volunteer and trustee recruitment
- refreshing our website and improving user experience
- working with the SIH SIG towards National Consensus Guidelines.

The progress we made this year is detailed below under the activities set out within our business plan along with a brief indication of future work.

In light of the progress we made and our limited resources the key deliverables for the next reporting period are:

- Increasing awareness by working with wider leak community with leak week collaborations
- Increase fundraising
- Optimising our website with a focus on security, resiliency, and maintainability
- Working with the SIH SIG towards the publication of national consensus guideline and considering next steps including the development of a registry

4.1. Working with our Medical Advisory Committee - Developing national consensus guidelines

A special interest group (SIG) for Spontaneous Intracranial Hypotension (SIH) was formed in late 2020 with the aim of developing and publishing consensus guidelines for the diagnosis and treatment of SIH as a result of spinal leaks or CSF-venous fistulae. It is composed of neurologists, neuroradiologists, neurosurgeons, headache nurse specialist, anaesthetists, pain management specialists and patient experts. The process is led by chair of the MAC, Professor Manjit Matharu, following a recognised methodology called AGREE II and supported by Dr Sanjay Cheema (both of UCLH and UCL) along with a subgroup of volunteers. Following the first guideline meeting held in January 2021 the members of the SIG continued working on the guideline development process throughout the reporting period. The SIG met virtually in March, May, July, September, October and December 2021. The March to October meetings concentrated on dealing with the questions agreed in the first meeting in January. For each question the evidence base along with expert opinion was presented to the SIG and guideline statements were proposed. Following a discussion and voting the statements were agreed if a consensus above 70% was achieved. If the threshold wasn't reached the proposed statement was modified through discussion and voted upon again. The meeting in December concentrated on the refinement of a diagnostic and treatment algorithm and a set of treatment standards (for service providers).

As part of the process a patient survey and healthcare professional survey was undertaken. The aim of the patient survey was to document the patient experience of SIH diagnosis and management as well as quantifying its impact on quality of life. It ran via an online survey platform for the month of March 2021 and the results were shared with the SIG in May 2021. The results were subsequently published in a paper entitled "Patient experience of diagnosis and management of spontaneous intracranial hypotension: a cross-sectional online survey" in *BMJ Open* journal in January 2022. As part of our commitment to raising

awareness of CSF leaks and the impact they have on those affected we chose to submit the paper to an open access journal and pay the publishing fee. The paper may be accessed at:

<https://bmjopen.bmj.com/content/12/1/e057438>

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), Prof Manjit Matharu (Professor of Neurology, UCL and Honorary Consultant Neurologist, NHNN), Clare Joy (Chair, CSFLA), Jenny people (Volunteer, CSFLA), Jessica Snape-Burns (Volunteer, CSFLA) and Tamsin Trevarthen (Trustee, CSFLA).

The aim of the healthcare professional survey was to assess the knowledge, attitudes, and practices of healthcare professionals regarding the diagnosis and management of SIH. It ran via the same online survey platform from mid June to the end of August 2021. The results were presented to the SIG in September 2021 and work later began to write a paper for submission to *BMJ Open*.

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.

Looking forward, the SIG will agree a draft guideline document which will be sent for review and comment to a host of professional bodies, e.g., Association of British Neurologists, internationally recognised experts and public consultation. Once the feedback has been analysed, we expect there to be at least one more (final) SIG meeting to discuss and vote on any changes. Only then can we submit it to a journal for publication. The work will not end there; we look forward to working on raising awareness of its existence with our MAC and the SIG.

Working through the guideline development process has made it painfully clear how little is actually understood about how leaks develop or heal or about the best course of treatment and the timeliness of any interventions (to name just a few!). We are excited to share that we are actively in discussion with our partners in UCL 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.

4.2. Growing our membership, volunteers and trustees

As of 31 March 2022, we had 85 individual members. Members can renew throughout the year and are sent out a membership pack each year and have access to our mailing list and newsletter.

We have successfully recruited and retained 2 new trustees and several volunteers including a volunteer coordinator who fulfil roles ranging from social media management, secretarial, fundraising, volunteer management to name but a few. We ran several volunteer meetings aiming to consult our volunteers on proposals or inform them of recent developments. More recently these meetings have focussed on wellbeing and have been successful in fostering a sense of community within our volunteer groups. We hope that initiatives like this will improve retention of skilled and passionate volunteers.

Since April 2021, trustees and volunteers have contributed over 2,000 hours of their time to the work of the CSF Leak Association. This ranges from attending board meetings, events, fundraising, publicity, social media, SIG related work and general administration. This is an impressive number and we appreciate every hour given by our dedicated team of volunteers who work together to deliver our aims.

Looking forward to the next reporting period we plan on reviewing our membership offering, continuing our wellbeing themed volunteer meetings while welcoming the talent and time potential volunteers and trustees may offer, especially when they bring knowledge or skills that complement those we already have or fill gaps. We would invite anyone who feels able and willing to

help in whatever capacity to reach out via office@csfleak.info. We understand, better than most, health-related limitations and competing priorities only too well, so we're always happy to work with you to find a task that fits with what you are able to offer.

4.3. Refreshing our website to increase user resources and improve user experience

Using the funds awarded to us by the Hospital Saturday Fund and with the help of our Website subgroup formed in late 2020 we launched our new website, csfleak.uk, in February 2022. The website has a fresh new look and includes more news articles, Leaker stories and CSF leak related events. From a technical perspective, it is built on the Craft Content Management System (CMS) which brings many benefits. It provides a modern and secure environment, rich with functionality that we can leverage to improve our digital offering to members, volunteers, and the public.

We are delighted to have received early positive feedback on the new website and wish to thank all the volunteers including those who worked on the subgroup, our testers, content writers and proof readers and of course the staff of Quisk who worked with us to deliver the project. In the first 6 weeks (12th Feb – 31st Mar 2022), we have had 6,471 new users to the website with most users coming from: United States (3,150), United Kingdom (1,768), Australia (258) and Canada (240). The way our users find the website is through: Organic Search (59%) such as Google, Direct (22%), Social Media (10%), Other (9%).

Looking forward, we plan on utilising the analytics gathered from the website to make data-driven decisions in the future, i.e., our most popularly visited pages and content, from where our page visitors come etc. We plan to continue to invest in our website with a focus on security, resiliency and maintainability. This includes moving to a new website hosting platform, upgrading to the latest version of Craft CMS, and introducing additional functionality to improve user experience. We aim to increase our user reach through Search Engine Optimisation (SEO) and curated content based on our most popular pages (Patient Experiences, Find a Doctor, Help & Support) and search terms.

We want to continue to develop the website with new features and content. There will be opportunities for volunteers to get involved in developing new content for the new site whilst also helping to maintain it. Particularly, news articles and medical journals, Leaker stories, fundraising or CSF leak related events. If you have any of those or are keen to get involved, please contact us at office@csfleak.info

4.4. Expanding our links with related charities, business and government bodies

Due to the COVID19 risks there were no in person events to attend this year. We were delighted to be able to attend a number of virtual events including:

- Recruiting a rare board by Findacure/Beacon
- 4th Annual Cedars-Sinai Intracranial Hypotension Symposium
- Maximising engagement with health care professionals
- Getting involved in research and trial design
- Understanding Health Economics: Preparing for Health Technology Assessment
- Rare chat on patient registries
- Raresummit21
- Rareshowcase22
- Virtual Headache Academy

We continue to engage with other organisations such as Rare Diseases UK, the Genetic Alliance UK, Brain Spine Foundation, Findacure/Beacon and other related charities.

4.5. Promoting research into the frequency, causes, diagnosis and treatment of CSF leaks

In January 2022 the results of the patient survey run as part of the guideline development process were published in BMJ Open. This was the first time the experience of patients with SIH in the UK was reported and to our knowledge the first of its kind anywhere. It demonstrated the multiple impacts of SIH on patients and their families in terms of pain, mobility, activities of daily living, financial circumstances and employment. The study showed a high level of disability and the impact of this is powerfully told in participants' own words included as figures.

Crucially, for many sufferers of spinal CSF leaks, the paper laid out the reality many sufferers face of late diagnosis following multiple visits to GPs or Emergency Departments, some specialists missing the diagnosis and reports of imaging being read as normal only to be later read as having had signs of SIH. Variability in management pathways was evident with, for example, some patients undergoing multiple diagnostic lumbar punctures despite research showing that opening pressures do not necessarily correlate with SIH.

The paper clearly demonstrates the need for guidelines however applicability of the results is inherently limited and more research is needed.

Looking forward to the next reporting period we expect to share the publication details of the healthcare professional survey and outline our progress with plans for more research using a registry as a vehicle to answer more of the questions that still plague understanding of this illness.

4.6. Increasing awareness of CSF leaks through all forms of media

We continue to maintain a strong presence on social media and publish our popular charity newsletter, titled 'Leaker Life'. The patient experience survey, conducted as part of the guideline development process, was promoted via our social media platforms and we were delighted to have had engagement from a larger than expected audience. Some key results were also posted via social media to highlight the need for guidelines and to make more people aware of the effects of a CSF leak on patients and their families. None of this would have been possible without our small but enthusiastic group of volunteers.

Looking forward to the next reporting period, we plan to increase activity on social media platforms and target platform/message combinations for our campaigns, e.g., attract volunteers, grow community engagement, raise funds. For the first time since 2018, we will be in a position to take part in an awareness campaign named 'Leak Week' and for the first time ever, we will be working directly with 'sister' charities in the USA (the Spinal CSF Leak Foundation) and Canada (Spinal CSF Leak Canada) to host an international campaign. If this goes well, we hope to make this a yearly event for us and to work with more charities to further our reach. In order to increase the social media and marketing skills of our volunteers we plan to enrol some of them onto online courses. These are being run by charities and are at no cost to the CSF Leak Association.

4.7. Fundraising

Due to the uncertainties of the pandemic and the focus on developing the guidelines and the new website, fundraising was extremely limited during this period.

Looking forward, we plan to increase income from more fundraising events, including those organised by individuals and by campaigns led by the charity. We have been encouraged by successful grant applications for our new website 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.

5. Donated Facilities and services

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

- Hosting by 34SP
- Independent examination by Alasdair Lawton
- MS365 from Microsoft
- Google workstation from Google
- Snap Surveys
- All the clinicians for their time and expertise in the development of consensus guidelines

6. Further Information

If you have any queries or questions about this annual report, would like more information on cerebrospinal fluid leaks or you'd like to get involved and volunteer with us, please drop us a line at office@csfleak.info or visit our website csfleak.uk

Appendix 1: Charity Trustees

Names of the charity trustees on date of approval of this Annual Report

	Trustee name	Office (if any)	Dates active (if not for whole year)	Name of person (or body) entitled to appoint trustee (if any)
1	Deborah Ogg		n/a	n/a
2	Shena Carrick	Secretary	7 December 2021	n/a
3	Clare Joy	Chair	n/a	n/a
4	Clare Sargeant	Treasurer	n/a	n/a
5	Steve Charles		1 February 2022	n/a
6				n/a
7				
8				

Names of all other charity trustees during the period, if any (for example, those who resigned part way through the financial period)

	Trustee name	Dates active (if not for whole year)
1	C Baldwin	up to 19 February 2022
2	M Boyd	up to 16 November 2021
3	Tamsin Trevarthen	up to 1 February 2022



CSF Leak Association

SC046319

Receipts and payments accounts

For the period

01 April 2021 - 31 March 2022

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Section A Statement of receipts and payments

	Unrestricted	Restricted funds	Total funds	Total funds
	to nearest £	to nearest £	This YE 31/3/22 to nearest £	Last YE 31/3/21 to nearest £
A1 Receipts				
Donations	2,398	-	2,398	12,267.40
Grants & Legacies	-	-	-	-
Receipts from fundraising activities	240	-	240	540.12
Gross trading receipts	28	-	28	50.62
Gross receipts from memberships	1,474	-	1,474	1,765.69
Gift aid	254	-	254	825.95
A1 Sub total	4,394	-	4,394	15,449.78
A2 Receipts from asset & investment sales				
Proceeds from sale of investments & assets	-	-	-	-
A2 Sub total	-	-	-	-
Total receipts	4,394	-	4,394	15,449.78
A3 Payments				
Expenses for fundraising activities	567	-	567	20.00
Governance costs	-	-	-	-
Payments relating directly to charitable activities:				
Website redevelopment & domain names	160	9,129	9,289	4,271.86
Publish survey in BMJ open	1,800	-	1,800	-
Outside Memberships	70	-	70	20.00
CSFLA Membership costs	69	-	69	50.89
Insurance, PO Box, zoom, postage	1,376	-	1,376	1,308.06
A3 Sub total	4,041	9,129	13,170	5,670.81
A4 Payments relating to asset and investment				
Purchases of fixed assets	-	-	-	-
Purchase of investments	-	-	-	-
A4 Sub total	-	-	-	-
Total payments	4,041	9,129	13,170	5,670.81
Net receipts / (payments)	353	(9,129)	(8,776)	9,778.97
A5 Transfers to / (from) funds	-	-	-	-
Surplus / (deficit) for year	353	(9,129)	(8,776)	9,778.97

CSF Leak Association

SC046319

Section B Statement of balances

		Unrestric ted funds	Restrict ed funds	Total YE	Total YE
		to nearest	website to nearest	31/3/20 22 to	31/3/20 21 to
B1 Cash funds	Balance at start of year	42,573	4,818	47,391	37,612
	Surplus / (deficit) shown on receipts and payments account	353	(9,129)	(8,776)	9,779
	Cash and bank balances at end of year	42,926	(4,311)	38,615	47,391

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

Date of approval

Signature

Print Name

28/4/2022		Clare Sargeant
24/06/2022		Clare Joy

Section C Notes to the Accounts

C1 Restricted funds

An application has been submitted to HSF for a grant for the redevelopment of the website. The outcome is not at this time known. If the funds are granted this will offset the negative balance on the website restricted fund. If unsuccessful, unrestricted funds will be used to offset the negative balance in the next financial year.

C2 Grants

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

C3a Trustee remuneration

If no remuneration was paid during the period to any charity trustee or person connected to a trustee cross this box (otherwise complete section 3b)

x

C3b Trustee remuneration - details

Authority under which paid	£
None	0
	0

C4a Trustee expenses

If no expenses were paid to any charity trustee during the period then cross this box (otherwise complete section 4b)

x

C4b Trustee expenses - details

	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

C6 Other information

The bank balance remains healthy in 2021/22. Income reduced this year with difficulties due to the pandemic halting the usual fundraising activities. In addition no large donations were received from individuals, facebook donations were down and less income was generated from memberships. The largest income came from donations and in particular we would like to thank Deborah Ogg and Lucy Sargeant. The remainder of our income came from online shop sales and gift aid on membership fees.

All expenditure relates to charitable activities and as expected was higher this year due to the work on the patient guidelines and the development of the new website. The largest outlay relates to the completion of the new website, the majority of this expenditure was funded from a grant received in 2019 for this purpose. A further grant has been applied for to pay for the expenditure above the initial grant. Another major cost this year was incurred by publishing research carried out during the year to inform the guideline group. Other costs are for zoom, insurance, PO Box, membership pack materials and postage. Also a fee was paid to enter a fundraising event which takes place in the next financial year. We still benefit from free website, cloud storage and email hosting.

We continue to work towards the aims set out in the business plan; this year achieving the aim of updating the website and reaching the final stages of producing the patient guidelines.

Our business plan concludes we need on average £1,540 per annum to maintain our current activities. Our business plan sets out our policy on reserves stating that at any one time we will maintain a two year reserve of £3,080. As detailed above, sufficient reserves are maintained.

APPENDIX 3



Report to the trustees/members of		Registered charity number		On the accounts of the charity for the period		Set out on pages	
Charity name		CSF Leak Association		SC046319			
Period start date		Period end date					
Day	Month	Year	Day	Month	Year		
1	4	2021	to	31	3	2021	(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*]					
		- 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					
		to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.					
Signed:				Date:		27th May 2022	
Name:		Alasdair Lawton					
Relevant professional qualification(s) or body (if any):		ICAEW Member No 7766919					
Address:							

* 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

Declaration

The Board of Trustees declare that they have approved the content of the annual report and its appendices.

Signed on behalf of the charity trustees:

Signature(s):		
Full name(s):	Clare Joy	
Position (e.g. Chair):	Chair	
Date:	9th July 2022	