



CSF LEAK ASSOCIATION

Annual Report 2019/20

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 **19 November 2020**. The report covers the accounting period from 1 April 2019 to 31 March 2020 plus an overview of forthcoming work, and is intended for consumption by the membership. It was approved by the Board on **22 October 2020**.

Annual Report from the Trustees

Introduction

The CSF Leak Association is now into its fifth year as a registered charity. This past year has been our most challenging to date and yet we have still managed to fulfil our aims.

All the current Trustees of the CSF Leak Association are made up of fellow CSF Leakers who have to try and overcome the many challenges associated with living 'life with a leak' whilst still progressing the charity's work. They have, and to continue to do this, incredibly well. Inevitably though, this is something people can only maintain for so long and therefore the charity is reliant upon a steady source of volunteers and people willing to help out.

Sourcing new volunteers and trustees has proved really challenging for the charity over a number of years but especially this last year. Repeated calls for volunteers have had a limited, albeit much appreciated, response. So inevitably the charity is at a junction.

This Annual Report seeks to set out our achievements this year but also the choices we now face. 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, our membership, fellow volunteers and our supporters for all they have done this past year. Each and every one of you has helped us towards our goals and we will continue to do at whatever pace we can

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.

All of the work carried out by the Association in the past year has been undertaken in order to further these aims and objectives.

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 6 August 2019.

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, expenses and publication of information.

The charity is governed by our Board of Trustees. We currently have four trustees, all of whom are unpaid volunteers. The Board manages the day-to-day running of the Association and meets formally via Skype. 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).

All 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 'uptime' 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 allows.

In order to ensure that the work of the charity continues to progress unconstrained by individual circumstances, we still hold all of our Board and Member's meetings via teleconferencing so that people can join in without having to leave their homes or even lie down if need be. We use Google's G Suite business tool to organise and manage Board work between meetings, including the use of instant messaging and video/tele-conferencing. This is proving invaluable as workload increases.

We also have a written resolutions mechanism in our constitution which enables certain decisions to be taken out with a board meeting, which not only deals with situations where insufficient Board members are well enough to attend a meeting, but also enables decision-making to be staged and avoid becoming a burden to those with health issues and limited uptime. This has worked well and, despite the challenges, we are pleased with what we have accomplished in such a short time.

Appendix 3 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.

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. The progress we made this year is detailed below under the activities set out within our business plan.

Growing our membership, volunteers and Trustees

As of 31 March 2020, we had 102 individual members. This is an increase on the previous year. Members can renew throughout the year and are sent out a membership pack each year and have access to our mailing list and newsletter.

Since April 2019, trustees and volunteers have contributed 983 hours of their time to the work of the CSF Leak Association. This ranges from attending board meetings, events, fundraising, publicity, social media and general administration. This is an impressive amount given the struggles we have had in recruiting volunteers and trustees. It demonstrates how much more we could achieve if more people were willing to offer their time. Our trustees and volunteers are our most important asset and we need to grow this resource.

Expanding our links with related charities, business and government bodies

We attended the Headache Academy in October 2019 and had a stand to provide our range of factsheets to attendees and answer questions. We continue to engage with other organisations such as Rare Diseases UK, the Genetic Alliance UK, Brain Spine Foundation and other related charities.

Working with our Medical Advisory Committee

The MAC met by way of teleconference in July 2019 and was looking to meet again in 2020 however the clinical demands posed by Covid-19 and the ensuing restrictions made this too difficult. The MAC welcomed another member when neurosurgeon Mr Ahmed Toma, UCLH, agreed to join in April 2019.

During the past year the MAC continued to progress work on a gap analysis and review of existing publications, groundwork and feasibility assessment for a first UK patients' day, continuing our work as a stakeholder with NICE, preparation for and invited speakers to the CSF Leak Study Day and liaison with government health departments.

The MAC continues to review recent academic publications on the subject of CSF leaks as compiled and reported by a charity volunteer. The MAC helped us draft and issue a press release regarding Covid-19 in March 2020 in response to concerns raised about how contracting Covid-19 might affect those with a CSF leak.

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

We facilitated the UK's first CSF Leak Study Day in September 2019 along with the Headache and Facial Pain Group, University College London Queen Square Institute of Neurology. This was very well attended and generated good discussion amongst attendees which included neurologists, neurosurgeons, nurses and patients.

It was an ideal opportunity for clinicians to share best practice in the UK, learn from published literature on practices from further afield and discuss the efficacy of different diagnostic and treatment approaches. The plan for further study days is to work towards establishing guidelines for the treatment of spinal CSF leaks however preparations for a second study day stalled due to Covid-19 restrictions.

We also awarded two bursaries to facilitate the attendance of two UK doctors to Spinal CSF Leak Symposium in Los Angeles and February 2020. Full feedback from this will be in our Leaker Life newsletter.

Refreshing our website to increase user resources and improve user experience

During this year our website passed the landmark of 1 million views since it was first launched! We have averaged about 20 000 views each month year. Our website formed the humble beginnings of this charity and we are keen to build on this success. The charity was awarded a grant from The Hospital Saturday Fund in September 2019 to enable the redevelopment of our website. We have now formulated our brief for this work and are seeking a partner to work with us on this exciting project . The Board of Trustees would like to express their sincere thanks to The Hospital Saturday Fund.

Expanding our range of doctor-endorsed factsheets

During the past year the MAC continued to progress work on a gap analysis and review of existing publications in the wider medical world. Once this is undertaken we can look to widen our factsheets to bring together some of the information we have found. In March 2020 we issued a press release regarding Covid-19 in consultation with the MAC.

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'. We also had a guest appearance on the Heads Up podcast in March 2020 (released on 30/3/20) and we featured on Medics 4 Rare Diseases Mystery Monday slot in August 2019.

Fundraising

We are excited to announce that Claire Secker will be running for us in the London Marathon. At the time of writing it is unclear when the marathon will now take place due to the ongoing impact of the Covid-19 virus however we have already received over £1390 in sponsorship donations following Claire's participation in the virtual London Marathon in October 2020. A big thank you to Claire and her husband Russell. Appendix 2 details our ongoing fundraising activities in full.

Looking ahead

Key to our success is the support from our trustees and volunteers. Without this we cannot achieve our aims. As reported last year, due to ongoing health challenges, we continue to struggle to maintain our Board and volunteer base. With this in mind, we have reviewed and extended our business plan until 2025 in order to focus our energies on the key deliverables which will meet the aims set out in our constitution and business plan based on our limited resources. Our key aims for the coming year are detailed below.

Increasing volunteer and trustee recruitment

We plan to research alternate sources of trustees and volunteers through third sector resources and networks. Through this we hope to expand our trustee and volunteer base. Finding and retaining trustees can be a challenge for many small to medium charities and it is amplified for our charity due to the nature of CSF leaks which affect all current Board members and many of our volunteers. With Covid-19 understandably dominating much of our health service resources, many rare diseases will slip even further down the agenda. This means we will need to 'shout even louder' to raise awareness of the CSF leaks to ensure people can access the help and support they need.

We need to find a way to recruit and retain consistent volunteers who are able to dedicate time to roles ranging from social media management, website management, secretarial skills, fundraising, volunteer management to name but a few. By widening our call for volunteers we hope we can provide better support for those already volunteering with us.

It may be that with the advent of Covid-19 that many people have found themselves with more time on their hands and are needing a way to get some sense of achievement and focus. We offer the unique opportunity of volunteering options that do not even require you to leave your home. We would invite anyone who feels able and willing to help in whatever capacity to note their interest with us. 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. Please reach out to us, if you can.

Refreshing our website to increase user resources and improve user experience

The very nature of CSF leaks mean that our website is a key resource for sufferers and it vital that this is kept up to date to fulfil the majority of our aims. As detailed above, the charity was awarded a grant from The Hospital Saturday Fund in September 2019 to enable the redevelopment of our website. We will finalise our brief for this work and employ a web design company to undertake this work. Through this we hope to expand the information available, develop our member services, improve our searchable database of UK/EU doctors with experience of CSF leaks and advance our online database of CSF leak journal articles.

Working with our Medical Advisory Committee

We are keen to build on the good work undertaken by the Medical Advisory Committee over the past few years as this is vital to progressing and expanding the diagnosis and treatment of CSF Leaks. Like many other health related charities, we firstly need to review how best to undertake this in light of the impact of Covid-19 on our health services. This is a key area of work to ensure the good work of the past few years is at least maintained this coming year with a view to progressing it when resources allow. We will work with our MAC to determine how best to utilise technology to deliver further study days and progress the work on guidelines.

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 www.csfleak.info

Appendix 1: Accounts for 2019/20

Introduction

Our bank balance has remained healthy during 2019/20 with modest expenditure relative to our income.

This year our largest income came from a £9000 grant in order to update our website. We still receive healthy income from online donation platforms such as Facebook and Just Giving, fundraising events such as the London Marathon and membership fees. As the London Marathon is postponed we will also receive monies for this during the next financial year. The remainder of our income came from online shop sales as detailed below.

All our expenditure has related to charitable activities. Our largest outlays were bursaries for two doctors to attend the 2020 CSF Leak Symposium in Los Angeles, insurance, our PO Box and material for membership packs. We still benefit from free website, cloud storage and email hosting.

Statement of Receipts and Payments	Year ended 31 March 2020	Period ended 31 March 2019
Total Income	17809.65	£13023.39
Donations (incl. individual donations – Gift Aid included where applicable)	£5759.61	£7775.35
Fundraising (Charity Yoga Party and London Marathon Donations thus far) – Gift Aid included where applicable)	£1472.42	£2649.15
Gross Trading Receipts - Online Shop Sales (wristbands, t-Shirts, stickers, ecards and so forth)	£108.66	£419.18
Receipts from charitable activities - Membership Fees	£1467.96	£1413.95
Other income (Website test income transaction and the Hospital Saturday Fund grant for website)	£9001.00	£765.76
Total Expenditure	£5037.96	£2382.24
Fundraising – London Marathon Ballot Fee	£396.00	£0
Governance costs	£0	£0
Payments relating directly to charitable activities:		
Website Domain and Hosting	£0	£137.60
Travel and subsistence	£204.56	£590.34
Professional Costs (membership of Alliance Scotland and Genetic Alliance which provides support to health charities)	£70.00	£20.00
Payment for material items, including banners, leaflets and membership packs	£725.08	£312.52

Other costs including insurance, PO Box, postage and CSF Leak Symposium Bursaries	£3642.32	£1321.78
Surplus/deficit for the year		
	£12771.69	£10641.15

Statement of Balances

	Total for Year ended 31 March 2020	Total for Period ended 31 March 2019
Opening cash at bank and in hand	£24840.52	£14199.37
Surplus (or deficit) for the year	£12771.69	£10641.15
Closing cash at bank and in hand	£37612.21	£24840.52

Notes to the Accounts for Year Ending 31 March 2020

1. Basis of accounting

These accounts have been prepared on the Receipts and Payments basis in accordance with the Charities & Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

2. Nature and purpose of funds

We have no investments, other assets, liabilities or contingent liabilities. Unrestricted funds are those that may be used at the discretion of the trustees in furtherance of the objects of the charity. The trustees maintain a single unrestricted fund for the day-to-day running of the charity. Restricted funds may only be used for specific purposes. Restrictions arise when specified by the donor or when funds are raised for specific purposes. During the year, the charity received a grant of £9000 to be used solely for our website update. We have not had to transfer any monies between restricted and unrestricted funds.

As detailed in the figures above, we do not have any deficits and have not donated any facilities or services this year.

3. Financial transactions with connected persons

No remuneration, benefits or expenses were paid during the period to any charity trustee or connected person.

4. Financial Performance in meeting Business Plan Aims

We have continued to work towards the aims set out in our business plan and in terms of finance, achieved our aim of getting a grant to update our website so that we can maintain our current reserves for other items in the Business Plan.

Our business plan concludes we need on average £1540 per annum to maintain our current activities. Our business plan sets out our policy on reserves which is that at any one time we will maintain a two year reserve of £3080. As detailed above, our main expenditures are the cost of producing publications, membership packs, insurance and costs in facilitating attendance at the Medical Advisory Committee, the CSF Leak Symposium and other awareness raising events.

Appendix 2: Independent Examiner's Report

APPENDIX 3



Independent examiner's report on the accounts v2							
Report to the trustees/members of	Charity name CSF Leak Association						
	Registered charity number SC 046319						
On the accounts of the charity for the period	Period start date			to	Period end date		
	Day	Month	Year		Day	Month	Year
	01	04	2019		31	03	2020
Set out on pages							
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. 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 Charities Accounts (Scotland) Regulations 2006. 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 accounts.						
Independent examiner's statement	In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]						
	1. which gives me reasonable cause to believe that in any material respect the requirements:						
	<ul style="list-style-type: none"> to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations 						
	have not been met, or						
	2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.						
Signed:	[Redacted]			Date:	18 th May 2020		
Name:	AZASDAR LAWTON						
Relevant professional qualification(s) or body (if any):	ICAEW Membership N° [Redacted]						
Address:	[Redacted]						

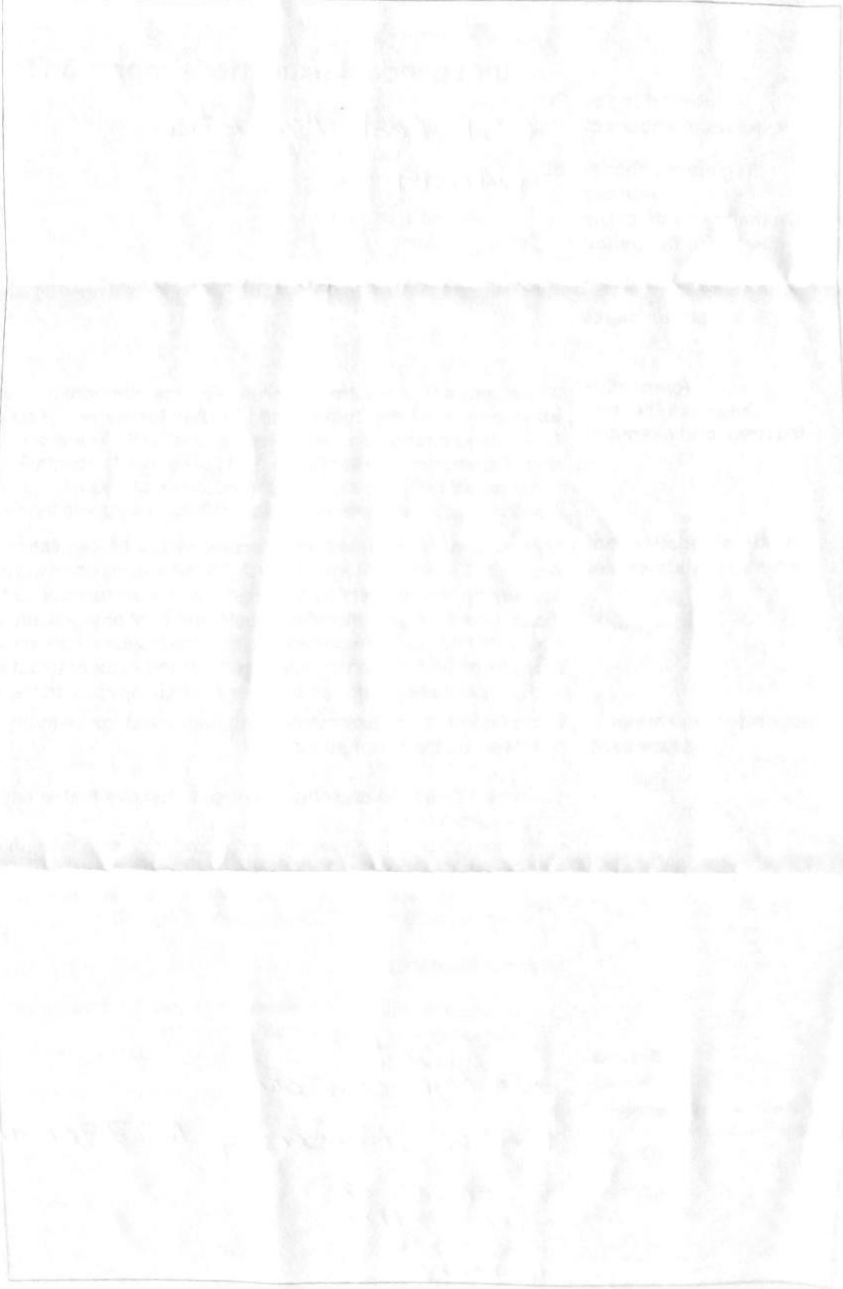
*Please delete the words in the brackets if they do not apply. If the words do apply, set out those matters which have come to your attention on the following page.

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



Appendix 3: 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	Treasurer	6 August 2019 - present	n/a
2	David Baldwin	Acting Secretary	n/a	n/a
3	Clare Joy	n/a	n/a	n/a
4	Tamsin Trevarthen	n/a	n/a	n/a


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	Susan Iacovou	16 April 2019 – 2 March 2020
2	Clare Sargeant	1 August 2018 – 23 July 2019

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):	Deborah Ogg	David Baldwin
Position (e.g. Chair):	Treasurer	Acting Secretary
Date:	22 October 2020	22 October 2020