



# CSF LEAK ASSOCIATION

## *Annual Report 2020/21*

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 **26th July 2021**. The report covers the accounting period from 1 April 2020 to 31 March 2021 plus an overview of forthcoming work, and is intended for consumption by the membership. It was approved by the Board on **9th July 2021**.

## Annual Report from the Trustees

### Introduction

The CSF Leak Association is now into its sixth year as a registered charity. This past year has been challenging 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 or carers of 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.

The charity is run solely by volunteers with no paid staff. Sourcing new volunteers and trustees has proved really challenging for the charity over a number of years but this last year we have prioritised volunteers and put in place a number of initiatives to aid recruitment. This has resulted in a much appreciated increase in the volunteer workforce who we are keen to nurture, train and retain.

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, members of our Medical Advisory Committee, members of the SIH special interest group 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 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, expenses and publication of information.

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

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 '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 and other commitments allow.

In order to ensure that the work of the charity continues to progress unconstrained by individual circumstances, we hold all of our Board and Member's meetings virtually 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 our work, including the use of instant messaging. This is proving invaluable as workload increases.

We utilise a written resolutions mechanism as outlined in our constitution which enables certain decisions to be taken asynchronously out with a board meeting. This adequately deals with situations where insufficient Board members are well enough to attend a meeting as well as having the benefit of reducing the burden associated with attending long meetings for those with health issues and limited uptime. This continues to work well and, despite the challenges, we are pleased with what we have accomplished in such a short time. In fact one could argue that as a Board of Trustees we were in a better position to react to restrictions imposed due to Covid-19.

Appendix 2 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.

### ***Working with our Medical Advisory Committee - Developing national consensus guidelines***

The MAC met by way of teleconference in June 2020 due to Covid-19 restrictions. The meeting focussed on how we could work towards the charity's aims during the pandemic and especially when the resources of the NHS were so stretched. After this meeting, work started towards forming a multidisciplinary special interest group to develop a consensus guideline on spontaneous intracranial hypotension. The process, led by chair of the MAC, Dr Manjit Matharu, will follow a recognised methodology called AGREE II. Invitations were sent in November 2020 to neurologists, neuroradiologists, neurosurgeons, headache nurse specialist, anaesthetists, pain management specialists and patient experts. We were grateful that the majority of invitees accepted the call to action and agreed to volunteer their time and expertise.

Ahead of the first guideline meeting held in January 2021 the members of the special interest group were tasked with listing the questions that should be addressed in a guideline. Once collated the long list of questions were voted upon and reduced to a more workable number. Each question was assigned to at least one member to lead on formulating a draft guideline statement. The second meeting was held in March 2021 where the special interest group discussed the first batch of questions. Draft statements were voted upon and if consensus was reached the statement was approved for inclusion in the final document. A series of meetings are planned throughout 2021 as well as a healthcare professional survey. A patient survey has already been completed. The results of the surveys will feed into the process so the group has views from patients and non-expert clinicians. It is hoped that a draft document will be ready for expert review and wider consultation in 2022.

### ***Growing our membership, volunteers and Trustees***

As of 31 March 2021, we had 88 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.

Despite the challenges this year we have successfully recruited and retained a new trustee and several volunteers who fulfil roles ranging from social media management, secretarial, fundraising, volunteer management to name but a few.

Since April 2020, trustees and volunteers have contributed 1,382 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 and we appreciate every hour given by our dedicated team of volunteers who work together to deliver our aims. 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. By widening our call for volunteers we hope we can provide better support for those already volunteering with us.

### ***Refreshing our website to increase user resources and improve user experience***

We are now in the process of developing our new website. We undertook a user survey in January 2021 which is helping to inform the design. We are aiming to increase the functionality of our site whilst making it more user friendly. It will also be

optimised for mobile devices as the majority of people are accessing the site from mobile devices. We hope to develop a member's area with resources specifically for our members and improve the current membership application system. It will also be a useful tool in advertising roles that need to be filled by volunteers as we are completely reliant on volunteers to undertake our work.

### ***Expanding our links with related charities, business and government bodies***

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

- Rarechat on Registries organised by Findacure
- Building your patient group data to drive research organised by Findacure
- Rarefest 20 a two day event run by Cambridge Rare Disease Network
- Accelerating Rare Disease Diagnosis by Findacure
- Importance of Real World Data Collection
- 8th Annual Conference of ILC Foundation Canada with Spinal CSF Leak Canada
- The Highs and Lows of CSF Pressure Problems a two day event by Duke University NC USA

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

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

In December 2020 we published a report on the results of a survey devised to better understand the Impact the Covid19 pandemic had on the care and treatment of patients with diagnosed or suspected CSF Leaks.

We organised for a volunteer student from Brighton University to undertake a literature review to examine the prevalence of CSF Leaks noted in previous research conducted on dural tears & punctures from medical procedures, spontaneous intracranial hypotension and cerebrospinal fluid leaks from injury. The review is due for completion in May 2021.

In March 2021 we conducted a patient survey to feed into the guideline process and understand the CSF Leak patient experience and specifically:

- How current provision meets or fails to meet the need
- Attitudes towards medical care received
- Perceived barriers to diagnosis and treatment
- Factors felt to be most important for good outcomes

The results of the patient survey will be shared widely once analysed.

### ***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'.

### ***Fundraising***

Claire Secker ran for us in the London Marathon event which took place in October 2020; due to the Covid-19 virus however she ran the marathon in North Carolina USA. 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. We continue 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 develop a strategy to expand our trustee and volunteer base and to set up a training module to help new volunteers work more efficiently and effectively. 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 most of our 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.

It may be that with the advent of Covid-19 that many people have found themselves with more time on their hands and are looking for 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***

During this next year we hope to have the new website up and running. There will be opportunities for more volunteers to get involved in developing resources for the new site whilst also helping to maintain it. We will be looking for news articles, Leaker stories or photographs of any 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](mailto:office@csfleak.info)

### ***Working with the SIH SIG towards National Consensus Guidelines***

Work will continue apace towards the completion of the guideline development process, consultation and ultimate publication. The work will not end there and we look forward to working on raising awareness of its existence with our MAC.

## 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](mailto:office@csfleak.info) or visit our website [www.csfleak.info](http://www.csfleak.info)



# CSF LEAK ASSOCIATION

## Appendix 1 Finance Report

### 2020/21

#### Introduction

Our bank balance has remained healthy during 2020/21 with reasonable expenditure relative to our income.

This year our largest income came from donations. In particular we would like to thank Vivienne and Martin Boyd who donated £6025 (inc gift aid) and Sion Lewis and Elizabeth Gunnion who donated £1000. We still receive a healthy income from online donation platforms such as Facebook and Virgin Money, fundraising events such as the London Marathon and membership fees. The remainder of our income came from online shop sales and gift aid on membership fees as detailed below.

All our expenditure has related to charitable activities. Our largest outlay relates to the deposit for our website development. We've also incurred costs for insurance, PO Box, membership pack materials and postage and the final CSF Leak Symposium Bursary payment. We've also paid for a Zoom account to enable us to facilitate large meetings and webinars with medical professionals and patient groups however we saved money on having to attend face to face events in light of Covid-19 restrictions. We still benefit from free website, cloud storage and email hosting.

| Statement of Receipts and Payments  | Year ended 31 March 2021 | Year ended 31 March 2020 |
|---|--------------------------|--------------------------|
| <b>Total Income</b>   | <b>£15449.78</b>         | <b>£17809.65</b>         |
| Donations (incl. individual donations – Gift Aid included where applicable)   | £12267.40                | £5759.61                 |
| Fundraising Events (for the Year Ending 31 March 2021 this included London Marathon and Tayside Health Board fundraiser - Gift Aid included where applicable) | £540.12                  | £1472.42                 |
| Gross Trading Receipts - Online Shop Sales (wristbands, t-Shirts, stickers, ecards and so forth)  | £50.62                   | £108.66                  |
| Receipts from charitable activities - Membership Fees   | £1765.69                 | £1467.96                 |
| Other income (for the Year Ending 31 March 2021 this was solely Gift Aid)   | £825.95                  | £9001                    |
| <b>Total Expenditure</b>  | <b>£5670.81</b>          | <b>£5037.96</b>          |
| Fundraising – Fee to enter 2021 London Marathon   | £20                      | £396                     |

|   |                                     |                 |                  |
|---|-------------------------------------|-----------------|------------------|
| Governance costs  |                                     | £0              | £0               |
| <b>Payments relating directly to charitable activities:</b>                                   |                                     |                 |                  |
| Website Domain Names and Website Redevelopment  |                                     | £4271.86        | £0               |
| Travel and subsistence  |                                     | £0              | £204.56          |
| Professional Costs (membership of Alliance Scotland)  |                                     | £20             | £70              |
| Payment for material items for membership packs   |                                     | £50.89          | £725.08          |
| Other costs including insurance, PO Box, postage and final CSF Leak Symposium Bursary payment |                                     | £1308.06        | £3642.32         |
|   |                                     |                 |                  |
|   | <b>Surplus/deficit for the year</b> | <b>£9778.97</b> | <b>£12771.69</b> |

## Statement of Balances

|                                   | Total for Year ended 31 March 2021 | Total for Period ended 31 March 2020 |
|-----------------------------------|------------------------------------|--------------------------------------|
| Opening cash at bank and in hand  | £37612.21                          | £24840.52                            |
| Surplus (or deficit) for the year | £9778.97                           | £12771.69                            |
| Closing cash at bank and in hand  | £47391.18                          | £37612.21                            |

## Notes to the Accounts for Year Ending 31 March 2021

### 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. We have £4818.14 remaining from the £9000 grant the charity received in 2019 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 updating our website, producing publications, membership packs, insurance and costs in facilitating attendance at the Medical Advisory Committee, the CSF Leak Symposium and other awareness raising events.

### **5. Independent Examiners Report on Following Pages**



**Independent examiner's report on the accounts** v2

|   |   |           |             |    |                 |           |             |
|---|---|-----------|-------------|----|-----------------|-----------|-------------|
| Report to the trustees/members of             | Charity name<br><b>CSF Leak Association</b>                 |           |             |    |                 |           |             |
|   | Registered charity number<br><b>SC 046319</b>               |           |             |    |                 |           |             |
| On the accounts of the charity for the period | Period start date   |           |             | to | Period end date |           |             |
|   | Day   | Month     | Year        |    | Day             | Month     | Year        |
|   | <b>01</b>   | <b>04</b> | <b>2020</b> |    | <b>31</b>       | <b>03</b> | <b>2021</b> |
| Set out on pages                              | [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. 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\*]

- 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: **18 May 2021**

Name: **MR ASD/MR RICHARD LAWTON**

Relevant professional qualification(s) or body (if any): **ICAEW Member**

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 2: 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       |                 | 6 August 2019 - present              | n/a   |
| 2 | Cerian Baldwin    | Treasurer       | 19 November 2020 - present           | n/a   |
| 3 | Clare Joy         | Chair           | n/a                                  | n/a   |
| 4 | Tamsin Trevarthen | Secretary       | n/a                                  | n/a   |
| 5 | Clare Sargeant    |                 | 10 December 2020 - present           | n/a   |
| 6 | Martin Boyd       |                 | 10 December 2020 - present           | 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 | David Baldwin | January 2016 to 19 November 2020     |

## 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:

|                               |   |  |
|-------------------------------|---|--|
| <b>Signature(s):</b>          |  |  |
| <b>Full name(s):</b>          | Clare Joy   | Tamsin Trevarthen  |
| <b>Position (e.g. Chair):</b> | Chair   | Secretary  |
| <b>Date:</b>                  | 9th July 2021   | 9th July 2021  |