

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 **6 August 2019**. The report covers the accounting period from 1 April 2018 to 31 March 2019 plus an overview of forthcoming work, and is intended for consumption by the membership. It was approved by the Board on **23 July 2019**.

Annual Report from the Trustees

Introduction from the Chairman

The CSF Leak Association is now into its fourth year as a registered charity and almost six years have passed since I and a small group of CSF leak sufferers from across the globe came together to establish its forerunner, the 'csfleak.info' website.

I could never have imagined back then just how much things would grow and develop, nor indeed the pace of that change. Like those that have gone before, 2019 has been another very active and in many respects ground-breaking year for our charity, its trustees and volunteers. I am honoured to have worked alongside such an enthusiastic and able group of people.

Our resources remain relatively modest, but our ambitions are big and bold. Much of our work is still carried out by our dedicated supporters and, for the most part, is commendably undertaken alongside the many challenges associated with living 'life with a leak'.

At times, progress can feel frustrating slow, but a sustainable, far-reaching and multidisciplinary transformation in health care cannot occur overnight and I believe that it is important to pause occasionally to remember what has already been achieved; we can be proud of the fact that we have already made very significant inroads in a number of priority areas and things are already much better now than they were before.

To that end, I hope that this report will provide an insight into the range of work that has been undertaken from April 2018 to March 2019 (as well as the months between then and the AGM), as we look forward to the year ahead with great optimism for continued progress and advancement in the field of cerebrospinal fluid leaks.

Things are moving apace with some exciting and hugely important milestones on the horizon, but none of this could happen, and the Board of Trustees could not do what we do, without the fantastic support of our membership, our volunteers and our supporters more generally. Thank you to all who've donated their time, their money and their expertise to help make life with a CSF leak a little easier for us all.



David Baldwin
CSF Leak Association chairman
(2015-2019)

Before I draw this introduction to a close, it is with very mixed emotions that I must also announce that I will be stepping down as chair of the CSF Leak Association at the AGM in August. It has been an absolute privilege to help establish and steer this organisation in its early years and I have met some truly amazing, inspirational people and made friends for life on this journey, but the time has now come for me to pass the baton onto someone else.

As I write this piece, who that will be remains unclear, however, and that brings me on to my final few thoughts: charities like the CSF Leak Association cannot exist on goodwill alone. They, we, rely heavily on people being proactive, getting involved and donating their time and energies.

If we are to achieve all that we have set out to achieve and build upon the firm foundations that our small but dedicated group of volunteers have laid, it cannot be stressed enough how vital it is that in the months and years ahead, more people get involved in the work of our organisation.

I very much hope that if you are reading this and you are not already a volunteer, you'll give volunteering with us active consideration. We understand 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.

If you are already involved or have been in the past, please know that we couldn't have arrived where we are without you and you have played an important role; many thanks to each and every one of you, or as they say up here in the Highlands, taing mhòr dhuibh uile!

Best wishes for all that lies ahead.

David Baldwin

Chair of the Board of Trustees

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.

Ensuring our work delivers our aims and objectives

As a Board, we continually review and reflect on our aims, objectives and activities, and each year we present a summary report to the membership at the annual general meeting. The report reviews what we have achieved and the outcomes of our work in the previous 12 months, plus a look at work that lies ahead.

This year's report looks at the success of each key activity (albeit not every activity) and the benefits they have brought to those people, groups and issues that we are set up to help. The report also helps us ensure our aim, objectives and activities remained focused on our stated purposes.

The focus of our work

Our main objective for the year focused on work with our Medical Advisory Committee (MAC) and developing a new volunteer management strategy and system, whilst still also progressing with a range of measures to raise awareness of and improve access to information about CSF Leaks.

The strategies we used to meet these objectives:

- Arranging MAC meeting in July 2018 via teleconference;
- Arranging MAC meeting held in February 2019 in Stoke;
- Continuing to work on a gap analysis and review of existing publications, in partnership with our MAC;
- Continuing to improve our online database of CSF leak journal articles, with direct links to PubMed/PMC etc., now on a regularly quarterly basis with literature reviews;
- Supporting preparation of the first UK doctor's study day on SIH (being led by the chairman of the MAC);
- Groundwork and feasibility assessment for a first UK patients' day;
- Preparation for mapping the patient journey to identify where resources would be best utilised;
- Development of a brief and project outline for redeveloping the web site and other online services;
- Applying for funding for the web site redevelopment project;
- Participating in the Findacure mentoring scheme;
- Reviewing our business plan and work plan, which will guide our work for the years ahead;

- Continuing our work as a stakeholder with NICE, contributing to consultations on new guidelines relevant to CSF leaks/SIH. Participating in the NICE scoping workshop for the guidelines on shared decision making;
- Attracting new members and sending them membership packs with new information and resources;
- Attending a number of medical conferences and events to promote the charity and CSF leaks/SIH, namely:
 - i. the first Headache Academy course in London, which included presentations by our MAC chair on CSF leaks and a lively Q&A session thereafter,
 - ii. The British Association for the Study of Headache (BASH) national meeting in Hull, which included a presentation on SIH by a member of the MAC, and
 - iii. RAREfest in Cambridge and Drug Repurposing for Rare Diseases conference in London.
- Partnership working with other organisations, including Brain Spine Foundation and other related charities;
- Reviewing and updating our online, searchable database of UK/EU doctors with experience of CSF leaks;
- Publishing our popular charity newsletter, titled 'Leaker Life';
- Preparing and adopting of a range of governance/management policies and protocols, including a review of our data protection policies (in line with the GDPR);
- Feedback surveys of our membership to inform and guide our work and development;
- Support for a number of awareness and fundraising events, including the Kilt Ride 2018 and a number of sponsored runs/walks and other events.



Clare Sergeant, representing the charity and raising awareness in 2018

Our main achievements, activities and initiatives, those we try to help and those we've worked with are summarised below:

Medical Advisory Committee

The period 2018/19 marked our first full year of having an operational advisory committee. We held two Medical Advisory Committee (MAC) meetings during the year: the first in July 2018 via teleconference and a second in February 2019 at Royal Stoke University Hospital in Stoke.

The meetings were attended by our supporting doctors (who are drawn from around the UK), along with member of our Board of Trustees Clare Joy and our Patient Representative, Sarah Mead, who met to discuss CSF leaks/SIH and to work together on initiatives to raise awareness, improve education and secure progress within the UK health systems with regard to treatment pathways.

The current committee comprises:

Dr Manjit Matharu, Consultant Neurologist, National Hospital for Neurology & Neurosurgery (Chair)
Mr James Walkden, Consultant Neurosurgeon, Aberdeen Royal Infirmary

Dr Anthony Ordman, Consultant in Pain Medicine
Dr Changez Jadun, Consultant Neuroradiologist, Royal Stoke University Hospital
Dr Simon Ellis, Consultant Neurologist, Royal Stoke University Hospital
Dr David Butteriss, Consultant Neuroradiologist, Royal Victoria Infirmary
Dr Brendan Davies, Consultant Neurologist, Royal Stoke University Hospital
Dr Heather Angus-Leppan, Consultant Neurologist, Royal Free Hospital
Clare Joy, CSF Leak Association trustee and MAC secretary
Sarah Mead, CSF Leak Association patient representative

The meetings give medical professionals, along with trustee/committee secretary Clare Joy and patient representative Sarah Mead, the opportunity to discuss routines and initiatives to improve health care provision for those suffering with this debilitating and under-diagnosed condition.

The meetings focus on:

- working towards the preparation and adoption of clear and consistent patient pathways for CSF leaks;
- a review of current literature and website information;
- gap analysis of current content including specific requests for guidance resulting from patient survey;
- the NHS Information Standard and the Association's road to accreditation;
- a proposed conference/doctors' day and patient day in the UK;
- securing the addition of CSF leak information on the NHS Choices and NHS Inform websites; and
- an agreement of annual objectives.

Whilst there is much work to do, all parties remain enthusiastic and positive about the future, secure in the knowledge that a firm working relationship has now been established between the charity and the MAC. The introduction of monthly meetings between the MAC chair and Board of Trustees representative has been a particularly welcome step and ensures a positive flow of information between all key stakeholders.

During the past year, a range of MAC-focused work has commenced and good progress made, many of which represent firsts for CSF leak care in the UK. We are very positive about what is planned and proposed for the year ahead, details of which will be announced in due course, as and when we're able.

It should be noted that by their very nature, a number of the initiatives will take time to come to fruition, whilst others will progress largely behind the scenes and cannot be publicised at this time. It is, however, an exciting time with significant work taking place. The change in status and recognition of CSF leaks/SIH from five years ago to the present day is apparent to all involved.

From its inception, the Board of Trustees and members of the committee itself have considered it vital that a range of disciplines involved in CSF leaks/SIH are well represented on the MAC. To that end, work has been undertaken in the past 18 months to increase the membership of the MAC and additional experts have been identified and welcomed on board.



Doctors and trustees in attendance
at the inaugural MAC meeting (2018)

The past twelve months also saw us introduce a 'spotlight on the MAC' feature in our quarterly charity newsletter, where we introduced MAC members to the CSF leak community. This has been well received and will be continued into the ensuing year.

The trustees would like to take this opportunity to express our thanks and gratitude to all members of the MAC, for not only offering their time and efforts voluntarily, but for their active and passionate support of what we, as a charity, are working to achieve.

We are especially thankful to Dr Matharu, currently the chairman of our MAC, for inviting us to attend the Headache Academy and allocating so much time to CSF leaks/SIH, and to Dr Davies for his presentation on CSF Leaks at the British Association of the Study of Headache national meeting. A special thanks also to Dr Ellis for hosting the MAC meeting in Stoke this year.

Awareness Raising

Factsheets & Publications

Our factsheets, website and social media resources are a vital component of our strategy for disseminating information to patients and medical professionals alike.

In 2018/19, we began identifying gaps in information with a view to developing new factsheets to ensure full coverage and facilitate easy access to vital, high-quality information.

Work now begins on preparing new publications, as well as reviewing and updating those existing. The latter will always be an on-going process, and we hope to establish a team(s) to help us keep our publications under review and continue to develop and publish more resources in the years ahead.

One recent notable success has been our factsheet explaining how different imaging technologies play a role in diagnosing and assisting treatment of CSF leaks. This was produced in early 2018 on the back of membership feedback.

Since publication, our imaging factsheet has been downloaded almost 1500 times and it is now included within new membership packs. We now have plans to produce a similar factsheet for cranial CSF leak imaging.



Imaging Techniques for Spinal CSF leaks factsheet

Headache Academy



MAC chair and consultant neurologist, Dr Manjit Matharu, welcoming delegates at the 2018 Headache Academy

We were given a fantastic opportunity to talk about our work, distribute our factsheets and advertise our website in October 2018, when the charity was invited to have a stand at the first Headache Academy held at the Royal College of Physicians in London.

The event was attended by approximately 150 neurologists and clinicians and covered both primary and secondary headache disorders.

MAC chair, Dr Manjit Matharu, organised the two day event and gave a presentation on spontaneous intracranial hypotension (SIH).

He then raised the profile of SIH further by presenting a case study of a patient with a CSF Leak, which lead on to a lengthy discussion with audience participation.

The event in general created a great deal of interest and we were extremely encouraged by the number of delegates who visited our stand to gather leaflets and find out more about the condition.

British Association for the Study of Headache

In January 2019, the charity was invited to attend the 8th Biennial British Association of the Study of Headache National meeting in Hull. The two day event is the largest headache meeting in the UK and was widely attended by delegates from all over the UK and abroad.

In attendance were 300 general neurologists, neurology trainees and general practitioners. Dr Brendan Davies, another member of the MAC, gave a presentation on SIH, he recommended the CSF Leak Association website as an excellent source of information and suggested the delegates visit our stand.

One of the five most interesting cases submitted to Novartis Pharmaceuticals headache case awards was “CSF venous fistula – a rare cause of spontaneous intracranial hypotension”, presented by Dr Sarmad Al-Araji. This, alongside Dr Davis’ presentation, was very successful at educating the delegates about many aspects of SIH and CSF leaks and bringing attention to the work of the charity.

Rare Disease Day – Holyrood Reception

For the second year in a row, the CSF Leak Association was represented at the Rare Disease Day/Rare Disease UK reception on Tuesday 20 February 2019 at the Scottish Parliament in Edinburgh.



The Scottish Parliament
Pàrlamaid na h-Alba

The event was chaired by Bob Doris MSP, conveynor of the Cross Party Group on Rare, Genetic and Undiagnosed Conditions, and included a number of key speeches from medical professionals and politicians.

Former trustee and founding member of the CSF Leak Association, Deborah Ogg, spent the afternoon in the company of a range of relevant stakeholders and Members of Scottish Parliament discussing the impact that rare diseases have on patients and their families. Progress and performance of the UK Strategy for Rare Diseases was also considered.

Medics 4 Rare Diseases

Alongside a number of contributions to surveys, research initiatives and policy development, the charity participated in the Medics 4 Rare Diseases red flag survey.

This initiative aims to raise awareness amongst medical professionals about rare diseases and the associated symptoms.

This is a very worthy project indeed, focused on those working at the frontline and those most likely to come across rare diseases through the course of their day-to-day work.



RAREfest 2018

The charity’s introductory cerebrospinal fluid leaks animation put the condition in the spotlight in October 2018 by gaining first place in the inaugural RAREfest RAREfilm festival. We topped an on-line poll for the best short film about a rare disease.

As a result, our film got a slot at the RAREfest event in Cambridge, where clinicians, researchers, scientists and the general public gathered to showcase the research being done in the rare disease field.



The CSF Leak Association’s short film came first in the RAREfilm online poll.

We once again also had a stand at RAREfest which attracted a great deal of interest amongst the attendees.

Our Online Presence

Our website continues to go from strength to strength, with most months now seeing between 20,000 and 30,000 views. In 2017 we saw almost 250,000 views and welcomed 130,000 visitors, rising to over 261,000 views and 137,000 visitors in 2018, which continues our year-on-year growth (see graph below).

Social media also continues to be an important element of our online presence, and we post to our Facebook page and Twitter profile multiple times per month. As well as producing our own content, we actively share and promote content produced by our sister charities and other organisations working in relevant fields.

We saw a notable increase in visitors and subscribers during Leak Week UK in 2018 and subscribers and followers have continued to rise over the past 12 month period. We now have almost 3000 followers on Facebook, over 1000 on Twitter and just shy of 400 on our new Instagram page.

We hope to develop a social media strategy in the next 12 month period, alongside a dedicated team of volunteers providing content and interaction.



CSFleak.info page views since April 2017. The period covered by this report is outlined in green.

As noted in last year’s annual report, we carried out a basic refresh of the website in early 2018. This improved the layout, access to information and general user experience, but was only ever intended as a stop gap solution until the website could be comprehensively redeveloped.

In Q1/2 of 2019, we applied to The Hospital Saturday Fund for grant funding to enable us to design and develop a new website, membership system, members' area etc. The application was prepared and overseen by trustee, Tamsin Trevarthen, and drew upon a preliminary brief and supporting documentation.

Work with Other Bodies and Organisations

We continue to work, and liaise, with other organisations, and view this as a key priority for the charity; pooling and sharing resources in areas of common concern and focus is vital to make the best of the limited resources that we currently have.

To date, we have worked/liased/joined with the following organisations and on a range of initiatives:

- Rare Disease (UK) – registered supporter and attended their rare disease event at the Scottish Parliament in early 2019;
- Genetic Alliance (UK) – registered support group;
- Medics 4 Rare diseases – registered CSF Leaks on red flag database;
- Brain & Spine Foundation – worked with them on a number of publications and now listed as the contact for CSF leaks;
- EDS UK – authoring an article for their Fragile Links publication;
- Orphanet – recently registered as a patient organisation;
- NICE – we are now a registered stakeholder in consultations of a range of guidelines. We participated in the scoping workshop in shared decision making representing the views of our members;
- Findacure – participating in the mentoring scheme.

In mid-2018, we made the tough but necessary decision to withdraw from the Spinal CSF Leak Community and our partnership with Inspire and Spinal CSF Leak Foundation. Whilst we were delighted to have worked with both organisations to deliver the forum over a number of years, as a small voluntary organisation, we have limited resources and must target them where they can have greatest effect and are most closely aligned with our organisation's aims and objectives and priorities.

We remain in contact with NHS Choices (England) and NHS Inform (Scotland), with a view to having CSF leaks and Intracranial Hypotension listed in their respective directory of medical conditions. This has, at times, been a frustratingly slow process, but we hope to see progress in the coming year.

We have a variety of other plans for future partnership working going forward, and will cover these in future newsletters and news/press releases. We would also like to take this opportunity to welcome Spinal CSF Leak Canada to the growing family of CSF leak-focused charities.

Newsletter and mailing lists

Our newsletter 'Leaker Life' remains well received and is delivered via our mailing list to almost 700 subscribers. It is also available to view via our website.

Polly Walker, former trustee and current volunteer, has once again done a sterling job as editor, however we will be looking for one or two more volunteers to assist with the newsletter going forward, to ensure that it can be delivered quarterly beyond 2019.

Average 'opens' for each email newsletter remains well above the platform average, with many more people reading the publication via



links on our website.

Each issue features a mix of informative articles on topical issues, reviews, interviews, opinion pieces, competitions and news.

We try to include a piece on members or fundraisers in each issue to help strengthen the sense of 'leaker community'. We regularly consult with the readership on the newsletter's content and adjust it accordingly.

This year, we decided to run articles on trustees, volunteers and members of our Medical Advisory Committee to help shine a little more light on those behind the organisation who work so hard – entirely voluntarily and in their own time – to help others and keep the charity moving forward.

Finances

In terms of the charity's fiscal health, we have had another relatively successful year and, once again, we finish the accounting period suitably positioned with regard to our current financial commitments and short-term plans.

We have seen a steady income over the financial year, in no small part thanks to some generous individual donations, donations from organisations and trusts, and a number of key fundraisers. We have also been successful in securing significant grant funding for website redevelopment.

We are, however, mindful of the fact that as we continue to grow and develop and, for example, move into new areas of work (such as research and education) the demand on resources will only grow. It will become necessary to identify larger funding and financing streams, and it is important that we ensure we are ready and able to capitalise on what is available to us.

With this in mind, the Board intends to identify a trustee and/or volunteer who is able to focus solely or mainly on fundraising, working closely with our existing treasurer and volunteer finance administrator. We will also actively explore ways of encouraging and supporting more fundraising and the identification of both initiative-specific and general grant funding sources. Full details of our financial transactions for the year can be found in Appendix 1.

Fundraising

It has been a busy year for fundraising, with a number of fantastic fundraising initiatives taking place. We saw another fantastic CSF Leak Tractor Rally up in the Scottish Highlands organised once again by Neil MacDonald, and we have had a steady stream of donations from people undertaking marathons, fun runs and sponsored walks, not least Jonathon Skinner and colleagues from Inverness PC World, who conquered the Loch Ness Beast race.

We have continued to receive regular income from Easyfundraising, Give As You Live and eBay/PayPal Giving Fund, which enable us to receive a donation for every purchase our supporters make via their website and at no extra cost to the shopper. Gift Aid also provides a welcome top up to many of the donations that we receive, and we always encourage people to tick the gift aid box, where applicable.

Having been accepted for both Facebook Fundraising and Amazon Smile last year, we have seen substantial fundraising and donations come in via those platforms and they are proving invaluable for enabling us to deliver our work. Facebook's integrated donation and fundraising tools are particularly useful for integrating with social media sharing.

Our trustees and volunteers have continued work on a fundraising pack, which should be available in late Autumn 2019, which we hope will provide additional support and guidance to people participating in or organising fundraising events for us.



Tractor rally event poster

This year we introduced CSF Leak Association e-Christmas cards. Our inaugural cards were designed in-house using wonderful photographs of Scandinavian Christmas ornaments, taken by UK-based Finnish CSF leak sufferer, Kariina Pirhonen.

We hope that this will become an annual tradition and look forward to covering other festivals throughout the year. We look forward to members and volunteers coming forward with suggestions and content.



CSF Leak Association e-Christmas card (photo: Kariina Pirhonen).



Regrettably, Vodafone and Just Giving opted to close down their free text message donation service in March of 2019. Whilst it was not a huge revenue stream for the charity, it was useful for fundraising events and encouraging ad hoc donations. We will examine what, if any, alternatives exist.

No matter the source, every penny is very important to us and we wish to note our thanks to each and every individual and business that has supported us this past year; we mean it sincerely when we say that, as an organisation, we simply could not operate without this sort of dedicated grassroots backing.

Legacies

Whilst it can understandably be a sensitive subject, legacy income is the largest single source of voluntary income to the charity sector. It is vital to the survival of many charities, including ours, and is a great way to help support our work well into the future.

During 2018/2019, we reached out to our membership and beyond to explain how they, their friends and their families could leave a gift in their will to ensure that support continues for other CSF leak sufferers and keep progress going in the years ahead.

Including a legacy gift to the CSF Leak Association in a will is easy and straightforward. Parties need only the information below to be included in their will to make sure that any legacy reaches us:

Cerebrospinal Fluid Leak Association
(Charity no. SC046319)
PO Box 5761
STRATHPEFFER
IV15 0AQ

Business Development & Planning

We continue to monitor our business plan forecast. Our key aims over the next three years are:

- Working with the MAC to improve access to information, diagnostics and treatment for CSF leak sufferers across the UK;
- Growing our membership, volunteers and Trustees;
- Expanding our links with related charities, business and government bodies;
- Promoting research into the frequency, causes, diagnosis and treatment of CSF leaks;
- Refreshing our website to increase user resources and improve user experience;
- Expanding our range of doctor-endorsed factsheets;

- Increasing awareness of CSF leaks through all forms of media; and
- Fundraising to ensure the long term viability of the charity.



CSF Leak Association Business Plan 2017-2022

As well as providing general direction for the charity, the business plan also plays a key role in grant funding applications, many of which cannot be made without at least 12 months of 'audited' accounts and a formal business plan being in place.

As we now have both boxes ticked, the door to new funding sources should now be unlocked. The timing for reaching this milestone meshes well with our intention to identify a dedicated fundraising volunteer.

The CSF Leak Association is governed by a constitution. The constitution was first adopted on 8 February 2016 and subsequently updated, most recently at the AGM on 1 August 2018.

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.

Membership

As of 31 March 2019, we have 87 individual members, with a number more embarking on the renewal process. This is down on the previous year, which is disappointing, but reassuringly we nonetheless see a steady stream of new members and a substantial mailing list/audience that is many hundred times larger than our membership.

What we have noted from the membership statistics is a tendency for members to join for one year, but not always renew thereafter. There are no doubt various reasons for this and consulting members on what motivates them to remain a member/not renew is an important piece of work that lies ahead. It is important for us to better understand what members want from the charity in return from membership, so that we can tailor our membership packs, services and benefits accordingly.

As in previous years, each member receives a membership pack, which includes copies of our new factsheets and infographics, medical accommodations cards for sufferers to use to advise people of their condition, a window sticker (for new members), post it notes (for returning members) and a wristband promoting CSF leaks and the Association.

While our aims are to raise awareness and promote CSF leaks generally, we nonetheless hope to develop a number of additional membership benefits in due course and improve the functionality of the online membership dashboard. It is anticipated that the latter will take place when the website is redeveloped.

Planning is also underway to hold the charity's first patient day in early 2020. Doctors from our MAC will be invited to give presentations on different aspects of CSF leaks and it will be a chance for our members to meet and share experiences and gain support from each other. Preparation for the event will call upon members to get involved with



CSF Leak Association awareness materials and publications, as issued at events during 2018/19.

organisation and delivery, and will very much be an event delivered by members for members.

We were regrettably unable to repeat our highly successful Leak Week UK 2018 in 2019. This was in part due to a lack of volunteers to help organise content and activities. Now that we have a volunteer coordinator in post and a developing volunteer strategy in place, we hope to be able to identify volunteers to help host an annual awareness week in 2020 and thereafter.

As part of Leak Week UK 2018, we announced our intention to establish focus groups to inform the work that we are doing; we were delighted to receive a significant number of notes of interest. Unfortunately, again due to resource constraints, we did not manage to deliver the planned project to our focus group during the 2018/19 period.

We do, however, remain committed to involving focus groups in our work and ensuring that our output is informed by our members and the CSF leak community; we hope to be in a position to make good progress with our focus groups in the year ahead. What this and other issues highlighted in this report have demonstrated is that one of the main bottlenecks in our project delivery path is our limited pool of volunteers, and we will work hard to try to deepen that pool in the year ahead.

Board of Trustees

The charity is governed by our Board of Trustees. We currently have five trustees, all of whom are unpaid volunteers. The Board manages the day-to-day running of the Association and normally meets formally on a monthly basis 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).

The majority of our Board, as well as our members, 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 sit up if need be. We now 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.

During the past year, there have been a number of changes within the Board of Trustees. Two trustees stepped down at the AGM in August 2018, for personal reasons. Between 1 April 2018 and 31 March 2019, two new Trustees joined the Board:

- Pete Marnick, who re-joined the Board in April 2018 and was appointed Treasurer at the AGM on 1 August 2018.
- Clare Sargeant, who had been a volunteer formally joined the Board as Secretary at the AGM on 1 August 2018.

We have a good, albeit small, team of dedicated people involved at Board level, with a beneficially wide range of abilities and experience; we are, however, entering a vital phase in a number of areas of work and it is considered that another two trustees would provide us with a more robust baseline.

In the spirit of openness, it is only right to report that turn over within the Board during the last two years (due to health and family/work demands) whilst understandable and unavoidable, has been higher than ideal or predicted. This has given rise to significant challenges for succession planning, continuity, consistency and project delivery.

With significant time and energy being invested in identifying new trustees and rearranging a number of priorities in the past year, we are pleased to confirm that the Board comprises a more sustainable quota once again, but we cannot rest on our laurels and must continue to plan for the longer term in terms of governance and oversight.

Finding and retaining trustees can be a challenge for many small to medium charities and it is amplified due to the nature of CSF leaks which affect all current Board members. We would urge any of our members who feel able and willing to help at Board level (or elsewhere) to note their interest.

We have an ambitious business plan and a lot is expected of us by the CSF leak community in the UK, but that can only be realised with practical as well as financial support.

Ask required, Appendix 4 details the charity trustees in office on the date of approval of this annual report.

Volunteers and Volunteering

The CSF Leak Association is a voluntary organisation; no one on the Board or amongst our volunteers is remunerated for the work that they do. Everyone involved has given up their own time – often whilst at the same time battling severe illness and disability – to try to make a difference for other people struggling with the condition. The sense of commitment and dedication to making a real, positive and tangible difference to CSF leak diagnosis and treatment is a huge strength of the association.

With the development our volunteering policy and business plan, a key aim of the association this year has been to identify jobs and tasks, and recruit volunteers to lighten the load on the Trustees. At present, we have volunteers carrying out our basic administration of membership and finance. We also have volunteers assisting with writing and proof reading our publications, production of our newsletter and regular reviews of publications and research.

For the period 2018/19, **over 1417 Trustee hours and 499 volunteer hours were logged for the CSF Leak Association.** Whilst the true figures are likely to be somewhat higher and part of our forthcoming work on volunteer management will include examining how best to capture volunteer activity in the future, this is nonetheless a huge amount of time and energy put into securing the objectives of the charity.

The logging of hours is a vital tool for not only assisting in match funding applications, but in demonstrating the time, effort and dedication being put into supporting this condition. It perhaps goes without saying that the Trustees would like to thank each and every person that has helped with and supported the work of the Association over the past 12 month period.

We have been very pleased to see a number of people not only come forward and volunteer their time and skills in the furtherance of our objectives, but in some cases take the lead on a number of initiatives. Without the help and support of people beyond the Board, the charity could not do the work that it does.

However, despite all of the many positives, identifying enough people to carry out all of the tasks that need to be done remains a significant task in itself and it would be remiss of us not to highlight the fact that this remains one of the greatest risks facing the CSF Leak Association.

The number of people getting involved with our work, whilst growing slowly, still does not keep up with the demands placed upon us by those seeking our help and support; we would once again appeal to anyone who may have some time to spare and would like to get involved in our work (or knows someone else who may fit into that category) to reach out to us.

We would like to express our thanks and gratitude to all who have volunteered with the charity over the past year. Thanks go in particular to Valerie McCluskie, Sarah Mead, Andrea Dilley, Ray Michael, Polly Walker, Jenny Pople and Andy Gardner. We would also like to thank Cerian Baldwin who performs the vital and demanding role of volunteer finance administrator.

Online Shop

We first launched an online shop in summer 2016, selling a variety of CSF Leak Association merchandise, from t-shirts to mugs, mouse mats to teddy bears. In 2017, we established a second shop, allowing us to expand the range of products available whilst keeping production within the EU. The shops are make-to-order and no stock is held by the charity.

The Association receives a small royalty for each item sold, so every sale helps to support the work that we do financially, as well as helping to raise awareness.

The shops (combined) continue to see a steady stream of visitors and sales, and we were pleased to see so many people flying the flag for the association. We also sell awareness wristbands on eBay, although there are plans to move this to an inhouse online shop.

The future of the second make-to-order shop remains uncertain due to the UK leaving the EU; we will have to make a decision as to whether to keep it open once there is greater clarity on what Brexit means for pan-European trade.



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: Other Optional Information (Activities & Events since 31 March 2019)

As a result of our last AGM being held in August 2018 and later than originally envisaged, activities and events during the four months immediately preceding the AGM fall outwith our accounting year. These periods will be realigned for future years.

So that members are fully appraised of where things stand at the time of the AGM, we have drawn together the key activities and events below for information only. They are listed under the principal activity headings to which they relate.

All activities and events, plus any associated income/expenditure, will be officially accounted for in the 2019/20 annual report.

Focus of our work

The MAC's fourth meeting was held in July 2019 via teleconference.

Medical Advisory Committee

Mr Ahmed Toma, Consultant Neurosurgeon, National Hospital for Neurology & Neurosurgery, joined our Medical Advisory Committee in Spring 2019. We would like to extend our thanks to him for volunteering his time and expertise.

Our Online Presence

We were delighted to learn that we have been successful in our application to The Hospital Saturday Fund. The charity has been awarded a grant that will enable the website redevelopment project to commence in 2019; it will be one of the charity's big priorities for the coming year. The Board of Trustees would like to express their sincere thanks to The Hospital Saturday Fund.

Work with Other Bodies and Organisations

With the UK Government's recent announcement that Amazon Alexa devices will be calling upon NHS Choice for home assistant medical advice, the Board of Trustees considers it to be ever more important that CSF leaks/SIH be included and covered well on the NHS Choices and NHS Inform platforms, so that patients are not placed at a disadvantage. We will continue our attempts to secure progress in this area throughout 2019/20.

Fundraising

In the early spring 2019, the charity applied for a place to run in the London Marathon in 2020. We are delighted to announce that we have been successful and have been allocated a place.

As places are hard to come by, we are delighted to have an opportunity to raise the profile of CSF leaks at such a famous and prominent event. We are currently identifying someone to run under the charity's flag.

Membership

We are pleased to have seen a slight uplift in membership since the close of the last financial year. As of 14 July 2019, the CSF Leak Association has 93 individual members.

Board of Trustees

We were delighted to welcome Dr Susan Iacovou to the Board of Trustees in April 2019. Susan brings with her a wealth of experience and a range of talent, and has taken over responsibility for recruiting and managing volunteers. She has already made significant inroads and we very much look forward to working with her in the years ahead.

Appendix 2: Accounts for 2018/19

Introduction

We have continued to maintain a healthy bank balance over 2018/19 with a number of generous donations. Our expenditure has remained modest while we save for large projects such as our website revamp.

We still receive the majority of our income from online donation platforms. 60% of our income came from online donations with the most successful being through Facebook which raised over £5703 alone. 20% of our income came from four fundraising events which raised the following amounts –

- The Kilt Ride 2018 £1508,
- The Harelees Hillbillys Line Dancing Christmas Party £164,
- Scottish Environment Protection Agency (SEPA) Christmas Ceilidh £156,
- Neil MacDonald's Tractor Rally which raised £800.

Membership fees generated over £1413 (11% of our income) and The North Midlands Neurosciences Ltd kindly donated £164 towards the cost of hosting the Medical Advisory Committee in Stoke on Trent. The remainder of our income came from gift aid and online shop sales as detailed below.

All our expenditure has related to charitable activities. Our two largest single outlays were insurance at £461 and our PO Box at £330. Since December 2018, we now also benefit from free website, cloud storage and email hosting.

Statement of Receipts and Payments	Year ended 31 March 2019	Period ended 31 March 2018
Total Income	£13023.39	£11123.21
Donations (incl. individual donations – Gift Aid included where applicable)	£7775.35	£6350.47
Fundraising (incl. The Kilt Ride, Tractor Rally and Christmas Party) – Gift Aid included where applicable)	£2649.15	£2407.41
Gross Trading Receipts - Online Shop Sales (wristbands, t-Shirts, stickers, mugs and so forth)	£419.18	£340.94
Receipts from charitable activities - Membership Fees	£1413.95	£2024.39
Other income (Gift Aid, which had to be applied for separately)	£765.76	£0
Total Expenditure	£2382.24	£3478.05
Fundraising	£0	£0
Governance costs	£0	£0
Payments relating directly to charitable activities:		
Website Domain and Hosting	£137.60	£297.90

Travel and subsistence	£590.34	£0
Professional Costs (membership of Alliance Scotland which provides support to health charities)	£20	£20.00
Payment for material items, including banners, leaflets and membership packs	£312.52	£1270.08
Other costs including insurance, PO Box and postage	£1321.78	£1890.07
	Surplus/deficit for the year	£10641.15
		£7645.16

Statement of Balances

	Total for Year ended 31 March 2019	Total for Period ended 31 March 2018
Opening cash at bank and in hand	£14199.37	£6554.21
Surplus (or deficit) for the year	£10641.15	£7645.16*
Closing cash at bank and in hand	£24840.52	£14199.37*

*When compiling this year's report we noted a typographical error in last year's finance report. In that report we stated our surplus as £7909 and therefore our closing cash at bank and in hand as £14463. The figures in the table above are now correct.

Notes to the Accounts for Year Ending 31 March 2019

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 no restricted funds and therefore has not had to transfer any monies between funds.

We've received no grants during this period. 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. Whilst reviewing the previous year's accounts, we noted that all expenditure that had been classed as trustee or volunteer expenses was actually reimbursement for out of pocket expenses for the purchase of material items needed for membership packs and fundraising events.

4. Financial Performance in meeting Business Plan Aims

We continue to work towards the aims set out in our business plan. It has been identified that we will require significant monies to revamp our website and we are seeking grants 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 and other awareness raising events.

Appendix 3: Independent Examiner's Report

APPENDIX 3



Report to the trustees/members of		Independent examiner's report on the accounts v2					
Registered charity number		Charity name CSF Leak Association					
On the accounts of the charity for the period		SC 046319					
Set out on pages		Period start date			Period end date		
		Day	Month	Year	Day	Month	Year
		01	04	2018	31	03	2019
		3			(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*]					
		<ol style="list-style-type: none"> 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					
		<ol style="list-style-type: none"> to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached. 					
Signed:						Date: 5TH JULY 2019	
Name:		MICHAEL LAWTON					
Relevant professional qualification(s) or body (if any):		ICAEW					
Address:		Membership					

*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

None

Appendix 4: 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	David Baldwin	Chairman	n/a	n/a
2	Peter Marnick	Treasurer	9 April 2018 - present	n/a
3	Clare Joy	n/a	n/a	n/a
4	Tamsin Trevarthen	n/a	n/a	n/a
5	Susan Iacovou	n/a	16 April 2019 - 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	Polly Walker	9 February 2016 - 1 August 2018
2	Deborah Lunnon	9 February 2016 - 1 August 2018
3	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):	David Baldwin	
Position (e.g. Chair):	Chairman	
Date:	23 July 2019	