CSF LEAK ASSOCIATION
Annual Report 2016/17

This annual report has been prepared for the Annual General Meeting on **2 May 2017**.

Annual Report from the Trustees

Introduction

It has been a busy inaugural year for the CSF Leak Association. Notwithstanding our limited resources and the health issues faced by most of our trustees and volunteers, we have made significant progress in a number of areas – including the publication of new resources and foundations for a Medical Advisory Committee - and have a range of ambitious plans for the future.

We began 2016 as a group of six enthusiastic volunteers committed to forming a charity within the UK to focus on cerebrospinal fluid leaks, and ended the year as a fully constituted Scottish Charitable Incorporated Organisation and registered charity. At the turn of the year, we opened for membership and are thrilled to now have over 50 members supporting our work.

We hope that this report will provide an insight into the range of work that has been undertaken over the past 12 months, as we look forward to the year ahead.

Our 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 outwith 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 taken in order to further these aims and objectives.

Ensuring our work delivers our aims and objectives

As a Board, we review and reflect on our aims, objectives and activities regularly, and each year we present a summary review to the membership at the annual general meeting. This review looks at what we achieved and the outcomes of our work in the previous 12 months. The review looks at the success of each key activity and the benefits they have brought to those people, groups and issues that we are set up to help. The review also helps us ensure our aim, objectives and activities remained focused on our stated purposes.

The focus of our work

Our main objectives for the year focused on the promotion of cerebrospinal fluid leaks and measures to raise awareness and improve access to information (and in support thereof). The strategies we used to meet these objectives included:

- Improvements, updates and additions to our website;
- Publication of a new overview leaflet, with input from two top UK neurologists;
- Reviewing and updating of existing factsheets, with work commenced to add new factsheets to the series;
- Creation of an online database of CSF leak journal articles, with direct links to PubMed/PMC etc.;
- Partnership working with other organisations, including the Spinal CSF Leak Foundation in the USA;
- Groundwork for the establishment of a Medical Advisory Committee;
- Reviewing and updating of an online searchable database of UK/EU doctors with experience of CSF leaks;
- Publication of an Android App for use on mobile devices, including phones and tablets;
- Commencing outreach work with other bodies, such as the Orphanet, EDS and brain/spine charities;
- Establishment of a quarterly Association newsletter, called 'Leaker Life';
- Preparing and adopting of a range of management policies and protocols; and
- Support for a number of awareness and fundraising events, including the Kilt Ride 2016, Tough Mudder North West, a number of sponsored runs/walks and other events.

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

<u>Website & social media</u>

We consider our website to be our key resource for sufferers and the medical profession to access information. Given the inability of many CSF leak sufferers to travel, it is the equivalent of our 'shop window'. We have therefore focused our efforts, in the first instance, on bolstering the website that we inherited from the information 'csfleak.info' group, adding new sections, updating others and introducing a new members' area.

Of particular note is our new library of journal articles, which links into the PubMed database and provides quick, easy access to quality papers on CSF leaks. The journal library was a considerable piece of work and can automatically search for new articles on CSF leaks, thus ensuring our database is up-to-date with all the latest research, while at the same time reducing the burden for site administrators. This is a valuable tool for anyone with an interest in CSF Leaks, not least given how limited the availability of marshalled, high-quality information and resources has been to date. It also links into our new android app, and it enables people to browse and share resources through their computer or mobile device.

We have also recoded and improved our interactive map of CSF leak sufferers around the world, and now have over 250 individual maps pins featured. Map pins can be added via our Android App, and in the near future members will also be able to add a pin via the online membership system. We have received feedback from a number of individuals who have found the visual representation of fellow sufferers around the globe a real support; despite the often isolating nature of the condition, they know that they are not alone.

More generally, the website continues to go from strength to strength, with March 2017 seeing over 16,000 views, which represents the highest volume to date. Much of the traffic continues to arrive via search engines (particularly Google), which a reasonable number of visitors visiting more than one page (the most popular including: *CSF leak symptoms*, *What is a CSF leak? Q&As with Dr Schievink* and I) and clicking through links to visit other related sites.

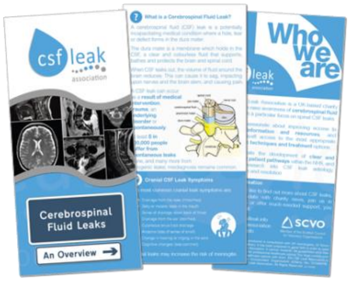
Work has also begun on developing a new website for the charity. The current site was established prior to the charity as part of the informal 'csfleak.info' initiative, and we effectively inherited it. While the existing site provided an excellent foundation to build upon, the Board decided that a more professional site, with updated content, revised sections and more user-friendly navigation and structure is necessary, and it is anticipated that this will be a key project for the coming year. A number of the new features on the current site have been developed with compatibility with any future site built in.

Social media also forms an important element of our online presence, and we continue to post to our Facebook page and Twitter profile multiple times per week. We now have over 1000 followers on Facebook and over 500 on Twitter. We hope to develop a social media strategy in due course, most probably in tandem with the new website.

Factsheets, leaflets & other resources

Our factsheets and other resources are an important way for us to disseminate information to patients and medical professionals. In 2016, we began reviewing and updating existing factsheets (some of which we inherited from csfleak.info), as well as identifying scope for additions to the series. This work will continue on a rolling basis into 2017 and beyond.

We were particularly pleased to be able to publish a folded A4 overview leaflet, which was released in late 2016 and features in our members' welcome pack, as well as being available as a PDF download.



The leaflet was prepared with input from Dr Manjit Matharu, consultant neurologist at the National Hospital for Neurology and Neurosurgery in London, and Dr Simon Ellis, consultant neurologist at Royal Stoke University Hospital. This is a peer reviewed leaflet – the first of its kind in the UK to focus on CSF leaks - and has already been warmly received by a number of NHS doctors who have so far been passed copies for reference and use.

As a brief summary, over 1500 copies of our 'What is a CSF Leak?' factsheet have been downloaded from our website to date. There have been almost 800 downloads of our new overview leaflet in a little over 5 months. Our terminology leaflet – which is due for revision in 2017 – has also proved popular with almost 600 individual downloads. We also produced a special 'Upright Headache? Think CSF Leak' leaflet to coincide with the Spinal CSF Leak Foundation's 'Leak Week 2017', which saw almost 300 downloads over a one month period.

Android app

We developed and published the CSF Leak Association 'Leaker Companion App' in late 2016. The app is free to download from the Google Play Store and provides fast access to key facts about CSF leaks, as well as links to our library of journal articles, our interactive global map of CSF leak sufferers and the Inspire Spinal CSF Leak Community, that we began co-managing with the US-based Spinal CSF Leak Foundation in summer 2016.

We hope that the app, amongst other things, will provide a quick and easy reference point during consultations with doctors, meetings with employers, disability support assessments etc. It also has a built in medical accommodations card, so can be used to request assistance by CSF leak sufferers on the occasion that they are out and about and may require a rest or to lie down.

The app has been downloaded over 80 times since publication, with users hailing from around the world (incl. Ethiopia and India). Further development, including the potential for an iOS app, will be reviewed after 12 months.

Medical Advisory Committee

We have approached a range of doctors with the aim of establishing a Medical Advisory Committee who will assist us in the production of factsheets and other resources, whilst also providing expert opinion and advice, and helping us improve patient pathways, diagnosis and care through the NHS and other services across the UK.

Our thanks go to Dr Manjit Matharu, who has provided significant support and advice to-date. At present, we expect that the committee will include doctors from neurology, neurosurgery, radiology and anaesthetics backgrounds. We hope to have the committee established and operational by the end of 2017.

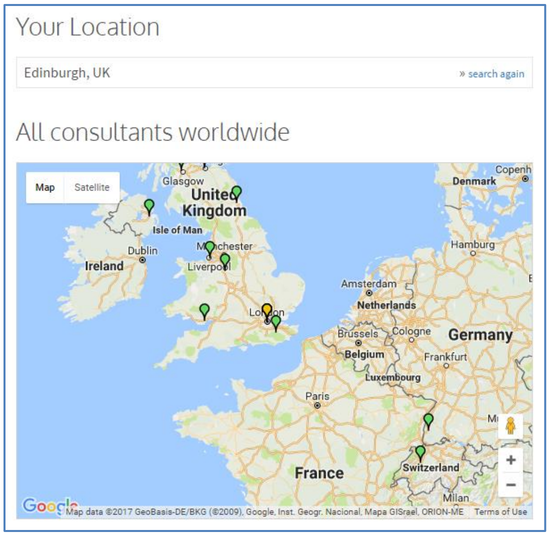
Consultant database

We have recoded and review our database of doctors with some experience of CSF leaks, and written to every doctor contained therein to reaffirm their approval for inclusion. It is now possible to search using an address anywhere in the world, not just a UK postcode, and our database includes international doctors who are known to have treated UK patients.

We stress at all times that the database is not a collection of recommended doctors, merely a list of those who are known to have treated leaks and with whom sufferers may wish to make contact.

Since the database was refreshed, we have seen over 3500 searches made, with almost 200 people opting to download a PDF copy of their search results. The search tool has also been integrated into our Android App.

With misdiagnosis still frustratingly common, one of the key hurdles for people suffering or thought to be suffering with a CSF leak in the UK is to find a doctor who has reasonable experience of dealing with the condition, and do so timeously. This database can help to assist people in jumping that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Edinburgh, UK

All consultants worldwide

hurdle and may help to circumvent delays, leading to swifter diagnosis and treatment.

Work with other bodies and organisations

The trustees have identified the need to work and liaise with other organisations as being a key priority for the Association; 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/liaised/joined with the following organisations and on a range of initiatives:

- Rare Disease UK – registered supporter
- Genetic Alliance UK – registered support group
- Brain & Spine Foundation – now listed as the contact for CSF leaks
- Spinal CSF Leak Foundation USA – co-manage Inspire Spinal CSF Leak community and collaboration over a number of activities and areas
- Inspire – partner patient advocacy organisation/co-manage Spinal CSF Leak community
- Orphanet – in the process of being registered as a patient organisation

We are currently in contact with NHS Choices, with a view to have CSF leaks and Intracranial Hypotension listed in their directory of medical conditions. We also continue to liaise with a number of doctors across the UK in order to spread awareness and work towards the preparation and adoption of clear and consistent patient pathways for CSF leaks.

We contributed to a recent consultation on the Implementation of the UK Strategy for Rare Diseases in England, and are very pleased to see that NHS England has recently announced that it will develop an implementation plan for its commitments under the strategy and that the Department of Health will coordinate implementation for those commitments that are not the responsibility of NHS England. Implementation plans for Scotland, Wales and Northern Ireland have already been published.

We have a variety of plans for future partnership working going forward, and will cover these in future newsletters and news/press releases. We also joined the Scottish Council for Voluntary Organisations (SCVO) in early 2016, which provides us with excellent access to third sector support, advice, guidance and news.

Newsletter and mailing lists

We identified the need for a newsletter early on in 2016 and published our first edition, entitled 'Leaker Life', shortly after in the Spring. Initially, it was envisaged the publication would be biannual, however the newsletter was so well received, and we have had no shortage of content, so the decision was taken to publish quarterly.

The newsletter is emailed out via our mailing list and has a wide reach, with an average of 55% percent opens, which is markedly higher than the average for this sort of mailshot.

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 a member or fundraiser in each issue to help strengthen the sense of 'leaker community'.

Given the amount of time and effort that goes into compiling each newsletter, the Board has taken the decision to limit access to its full content to members of the Association, while non-members will have limited access to some new articles and full access to back issues.

It was felt that this struck the right balance between keeping the newsletter available to members/non-members, while focusing some of our efforts more closely on those who have chosen to actively support our work. It is likely that members only content will begin to appear as the new website is rolled out (as this will better facilitate such content).

Fundraising

Despite being our founding year, the period 2016/17 was a busy year for fundraising, which a number of fantastic fundraising initiatives taking place, from the inaugural Kilt Ride (which will make a returrn in 2017) to fire walking, sponsored walks and runs to gruelling Tough Mudders. The trustees have been bowled over by the support given to the Association in this its first year.

We also continue to receive regular monies from Easyfundraising and Give As You Live. These are free portals through which internet shopping is carried out. For each transaction made, a small percentage of money makes its way to the CSF Leak Association. There is no cost to the shopper, so it's an excellent way to generate donations without any cost to yourself. We now have over 80 supporters on Easyfundraising alone.

The trustees have begun to explore options for lending more support to those within to raise money for the Association, potentially through the preparation of a fundraising pack and expansion of our websites fundraising pages.

Business development & planning

A substantial area of work for the forthcoming year will be the development of the Association's business plan.

The Board held a dedicated strategy meeting in 2016 with a view to the preparation of a business plan to help guide our work and priorities going forward. Foundation work for this was then carried out in the second part of 2016.

We initially sought a suitably experienced volunteer to assist with drafting the document itself based on identified short-, medium- and long-term goals, however this approach has regrettably not born fruit and no volunteers have come forward.

It is therefore intended to engage the services of a professional consultant, using the Association's funds to cover the costs. We have begun to identify potential candidates for the work and hope to make progress on the business plan project soon after the election of the new Board at the AGM.

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

Membership

We opened for membership in January 2017 and, as of 1 April 2017, have over 50 individual members. This is a fantastic number to gain so quickly, and the trustees would like to express their thanks and gratitude to those who have both supported the Association from the outset and have joined us so quickly in membership.

Membership applications can be made online, with payment processed by PayPal, or via paper application form. To date, the vast majority of members have made use of the online system. Once their application has been received and approved, each member receives a membership pack, which includes copies of our new doctor-endorsed overview leaflet on the causes and symptoms of CSF Leaks, medical accommodations cards for sufferers to use to advise people of their condition, factsheets, a window sticker and a wristband promoting the CSF leaks and the Association.

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

Volunteers & 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.

At the time of writing this report, over 673 volunteer hours have been logged by the Trustees with regard to work for the CSF Leak Association since February 2016, and we are sure that there have been many more hours spent by supporters and volunteers in addition. 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.

During the second half of 2016, the Board began work on a volunteering policy. There is still a significant amount of work to be done on this – not least given the ever increasing amounts of red tape involved with volunteering and employment issues – and it will be a project taken forward by the new Board in 2017/18.

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 case take the lead on a number of initiatives, some of which have already been published, others of which will be so in the coming months. Without the help and support of people beyond the Board, the charity could not do that work that it does.

We introduced a database of volunteers in summer 2016 so that we can keep track of those who have expressed an interest, and we hope that it will continue to grow. Currently, the database is used only when a project requiring is due to commence, however we hope that following the development of our volunteering policy and our business plan, we will be able to take a more strategic and proactive approach to volunteering in the near future.

Online Shop

Summer 2016 also saw the launch of our online shop, selling a variety of CSF Leak Association merchandise, from t-shirts to mugs, mouse mats to teddy bears. The Association receives a small royalty for each item sold, so every sale helps to support the work that we do.

Some of the t-shirts and mugs feature logos designed by members of the public through a competition held in summer 2016, which not only help to raise awareness of CSF leaks and promoting the charity, but have helped to keep people involved in the work that we do.

This report was prepared on behalf of the Board of Trustees by **David Baldwin (Chairman)**
It was approved by the Board at their meeting on **10 April 2017**.

Questions? Need more information?
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