



CSF Leak Association

Annual General Meeting Minutes

Date:	6 August 2019
Time:	19:00
Location:	Skype
Present:	Susan Iacovou (SI), David Baldwin (DB), Clare Joy (CJ) and Tamsin Trevarthen (TT), Cerian Baldwin (CB), Anne MacInnes (AM), Andy Gardner (AG), Sandie Moore (SM), Russell Secker (RS)
Not Present:	
Apologies:	Frank Donnerstag, Deborah Ogg, Dr. Manjit Matharu, Dr. Anthony Ordman, John Baldwin and Vivian Baldwin who have submitted proxy votes which the Chair can exercise at their discretion.
Declaration of interest:	None registered
Appointment of Minute Secretary:	CB agreed to take the minutes.

Agenda items		Actions
1.	<p>Approval of Minutes of the Previous AGM</p> <p>DB proposed and TT seconded that the minutes from 1 August 2018 be agreed a true and accurate reflection of the meeting. The minutes were approved.</p>	
2.	<p>The Trustees' Annual Report 2018/19</p> <p>DB noted the key achievements in the Annual Report 2018/19. Approval of the Annual Report 2018/19 was proposed by DB and seconded by SI. No queries were raised.</p> <p>SI suggested the circulation of a summarised form of the Annual Report to members.</p>	SI
3.	<p>Financial Report & Summary of Accounts for 2018/19</p> <p>CB presented the Financial Report & Summary of Accounts for 2018/19 verified by chartered accountant Alasdair Lawton. The Financial Report & Summary of Accounts for 2018/19 was noted and no queries were raised. Approval of the report was proposed by CJ and seconded by SI and the Report was approved.</p>	

	<p>The Board again would like to take this opportunity to extend its thanks and gratitude to all our fundraisers and supporters and to Alasdair for his help as independent examiner.</p>	
4.	<p>Medical Advisory Committee Update</p> <p>CJ thanked the doctors and volunteers on the MAC who have volunteered a significant amount of time. She noted their incredible dedication and hard work throughout the year. CJ noted the multi-disciplinary nature of the CSF leaks and the work that has been done to reflect this in the MAC membership.</p> <p>Key activities of the MAC this year have been:</p> <ul style="list-style-type: none"> - responses to NICE and SIGN consultation work; - quarterly literature review; - work to set up a doctors study day; - ground work for medical research; - ground work for developing a patient pathway; - support to attend medical conferences; and - sharing and review of our publications. <p>A key event was the Headache Academy where CSF leaks were in the spotlight. This raised many challenging issues and it was good to witness doctors debating these and challenging each other. This kind of event leads to important networking and new learning which we hope will ultimately result in better diagnosis and treatment options within the UK.</p> <p>SM queried how a patient pathway is developed. CJ explained that the main steps are usually a combination of a literature review and consultation with leading experts in the field to develop an agreed set of guidelines supported by published medical research. As there are currently a limited number of published medical research papers into CSF leaks, it is likely that in the interim consensus guidelines, agreed between the various medical experts, will be developed with a view to undertaking more medical research in the future so that a formal patient pathway can be established.</p> <p>AG asked about whether there is a list of topics requiring medical research. CJ confirmed that this is currently under review by the MAC. In addition, a literature review which is identifying what research has already been done, what is underway and what gaps there are is being undertaken by a PHD student. We hope to build on this during the proposed doctors study day. Once a list is compiled we can then work with the medical experts to identify research proposals and grant funding.</p>	
5.	<p>Election of Independent Examiner</p> <p>DB proposed resolution no. AGM/2019/1 seconded by CJ. That Alasdair Lawton be re-appointed as independent examiner to verify the Association's accounts for 2019/20 (unless unforeseen or extenuating circumstances required the Board to appoint a different independent examiner).</p>	
6.	<p>Membership Subscriptions for 2019/2020</p> <p>DB proposed resolution no. AGM/2019/2 to maintain the existing annual subscriptions and subscription categories required for qualification as members of the Association. This was</p>	

	seconded by SI. No objections have been received, therefore this proposal has been adopted.	
7.	<p>Constitution Amendments Resolutions</p> <p>DB proposed resolution 2019/3 which will amend the constitution in terms of office-bearer elections and acting up. Seconded by TT. No objections have been received, therefore this amendment has been adopted.</p>	
8.	<p>Appointment of Patient Representative</p> <p>DB proposed Sarah Mead as Patient representative for the year 2019/20 and this was seconded by CJ and Sarah was duly appointed. DB thanked Sarah Mead for her help over the last year.</p> <p>In future years, the Board proposes that applications be invited from amongst the membership prior to the AGM. A shortlist of names would then be drawn up by the Board after consideration of the applications and put forward to the AGM for a final decision.</p>	
9.	<p>Election of Charity Trustee Bearers</p> <p><u>Election of Office Bearing Trustees (Chairman, Secretary and Treasurer)</u></p> <p>The following existing trustees are proposed by the Board to act up in respect of the stated posts:</p> <ul style="list-style-type: none"> ▪ Susan Iacovou (Acting Chair) – DB proposed and TT seconded. ▪ David Baldwin (Acting Secretary) – CJ proposed and SI seconded. <p>The following member is proposed by the Board for election as trustee and treasurer:</p> <ul style="list-style-type: none"> ▪ Deborah Ogg (Treasurer) – DB proposed and CJ seconded. <p>No objections were received and the above Office Bearing Trustees were duly appointed.</p> <p><u>Election of non-Office Bearing Trustees</u></p> <p>The following existing trustees are proposed by the Board for re-election:</p> <ul style="list-style-type: none"> ▪ Clare Joy – DB proposed and SI seconded. ▪ Tamsin Trevarthen – DB proposed and SI seconded. <p>No objections have been received and the above non-Office Bearing Trustees were appointed.</p> <p><u>Former Trustees and Office-bearers</u></p> <p>The Board would like to thank and extend their gratefulness to former trustees, Pete Marnick and Clare Sargeant, who have not sought re-election at the AGM. Both Pete and Clare have contributed a huge amount to the charity over a considerable period, with Pete being a founding member and twice trustee, and Clare volunteering for a number of months before then joining the Board in 2018. We could not have made the progress that we have made without their input, and we wish them both well for the future.</p>	
10.	<p>Volunteering</p> <p>SI highlighted the importance of our volunteers in supporting and developing the work of the charity. At present we have 38 volunteers on our volunteer database with 50% currently available to volunteer and 8-10 of those able to regularly contribute. The majority of our</p>	

	<p>volunteers suffer with a CSF leak or have a family member or friend with a leak. As CSF leaks are not currently high profile, our pool of volunteers is quite restricted but hopefully through our continued awareness raising this pool will broaden.</p> <p>AG asked whether we have approached any high profile CSF leakers. We have approached a number of celebrities in the past and will continue to in the future. SM highlighted the One Show as a possible avenue. We will look into this and progress it.</p> <p>As highlighted on our Agenda, the CSF Leak Association only exists because of the dedicated work carried out by trustees and volunteers, almost all of whom also suffer from CSF leaks. With a number of trustees departing over the past year due to home/life commitments and health, opportunities exist for people to get involved and assist in enabling the planned growth of the charity. The trustees would encourage anyone with an interest in our work to get in touch via our dedicated email address and discuss how they can get involved and help to support, shape and progress our work: volunteer@csfleak.info</p>	SI
11.	<p>Any Other Business (AOB)</p> <p>SI expressed the leaker community's thanks to DB for his work in setting up the charity and for his personal support to a number of people. TT also noted DB's personal investment in the charity and for all his work behind the scenes which she recognised has often come at a personal cost. SM shared her gratefulness for the website and work that DB has done. CJ noted how inspirational David's work has been and that this helps motivate her in her volunteering work. SI and DB also noted thanks to CB.</p> <p>DB mentioned we have a place on the London Marathon and we will be advertising for someone to run for us. RS is interested so we will contact him to discuss this.</p> <p>AG asked about the patient day as his company would be able offer the use of their premises and TV studio area in London. This is a fantastic offer and we have still to confirm the location and date so will come back to AG to discuss.</p>	SI SI
12.	<p>Date for Annual General Meeting 2020</p> <p>The date and time of the 2020 annual general meeting will be confirmed and advertised nearer the time. It is likely to be slightly earlier in the year.</p> <p>Meeting closed at 20:14.</p>	
<p>Respectfully submitted by: Cerian Baldwin</p>		<p>Date: 6 August 2019</p>

NB. These minutes remain draft until approved by the next AGM.