

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Committee Meeting – Winchester Hotel, Winchester, Hampshire.
16th February 2019, Start time 12:00

Minutes

Attendees: Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mike Cain (MC), Della Brookman (DB), Ian Bennett (IB), Roger Brookman.

1. **Expenses Policy review.** JM Proposed that the groups policy re travel expenses to meetings should be clarified such that attendees at management meetings should be able to claim petrol allowance of 25p per mile or standard rail fares. **AGREED.**
2. Items from previous meeting:
 - a) **New membership form.** After our last discussion of the Membership Form it was unclear if the membership form presently on the web site was the correct one. **IB/JM will check this and ensure that the correct version is loaded onto the web site.**
 - b) **Fundraising objectives/Mission statement.** It was agreed that in order to pursue future funding opportunities we need to have a succinct description of our Mission Statement and our Funding Objectives. **AL will produce a draft for consideration.**
3. **Updated Constitution.** AL wished to record thanks to all who had updated the Constitution and got it accepted and registered with the Charity Commission. It was agreed that we now have to ensure that the new Registration number is reflected on our documentation. **DH Will find out from the Charity Commission how long the previous registration number will be in service/ displayed.** At present both registrations are visible on the CC web site.
4. **Funding room hire costs for meetings?** AL had done a survey of current meeting organisers. Current meeting room hire costs are about £500/yr (2 meetings per venue per year). After a brief discussion it was agreed that the Group set an annual budget of £1000 to provide for the cost of local meetings. **JM will put this into effect.** Organisers will need guidelines to help them in setting up and running these meetings. **AL agreed to provide a draft guideline document.**
5. **Establishing more regional meetings.** JM Expressed a concern that several meeting organiser volunteers had stepped forward but as yet there had been no follow-up. In his view there needed to be some mechanism to kick into action the these volunteers. It was agreed that **AL would include a summary of the various types of meeting in the draft guideline** to give the new volunteers some ideas of what had been found to work. JM/IB would meet to discuss how best to provide practical support to these new volunteers.
6. **Use draft research assessment method as a trial?** AL prepared draft scoring system for research grant application. After discussion it was agreed that this document should be used to assess Applications for Research Grants. The mechanism would be that the Research Committee would do the assessment and the provide Trustees with a recommendation. Trustees were then free to consider that recommendation as part of their decision making process. **It was AGREED to implement this approach as a trial for a year.**
7. **2019 AGM.** After discussion, the following general outline was agreed: Two speakers following the AGM until lunchtime, Lily and Amber giving presentations on their previous 12 months (**MC to contact Ambers family; IB to do the same for Lily**). PM session; possibly the Exeter research report (maybe better 2020?) (**IB/JM to determine/set up**) Carers Trust presentation & Rebecca Schuler (**AL to set up**).
8. **Safeguarding.** As a result of our earlier discussions and consulting with the Charity Commission (who had not yet come to a clear view), Adam had listed three “categories” of possible intervention:
 - a) If a member **directly expressed a wish** that action be taken
 - b) If a member was observed at a meeting to be having difficulty, **consult the member and if they then agreed,** refer to Local Authority.
 - c) Discuss among Trustees and then refer **as a result of observations** at a meeting.

JM had talked with his local MS group who interact frequently with their members. Their safeguarding “rules” defined a clear boundary of their safeguarding – only inside the premises where they work. As we have not defined any such boundary, some Trustees were strongly opposed to the third option. There was more agreement about the first two. ??JM/IB to seek copies of policies from organisations they visit?? **AL would prepare a draft taking this information into account.**

9. **Facebook Groups.** DB had had cases where abusive messages had been posted to the Facebook group which she was managing on behalf of the groups members. AL confirmed that the group supports DB in the actions which she takes on our behalf in managing that group.

There is still some confusion between the two HSP Facebook Pages, this may well be contributed to because the front page link on our web site links to the original “Unite” group. **It was agreed to change this link to the group managed by Della for UK HSP members (Action DH).**

10. **Newsletter.** There have not been many contributions thus far for the next issue of Newslink and the next issue may be pushed into March as a result. IB is concerned that as a result the timing of the notice to members for the AGM may not “fit” with the timing of the following issue. It was agreed that we would plan to issue the AGM information and invitations separately this year. **(Action JM/IB/AL)**
11. **Potato Pants Festival.** IB said that the festival had raised £2,400 so far this year. There was still more to come as The Old Thatch pub was going to have a “warm up” Easter event and this was likely to raise limited funds but plenty of awareness of the Festival. Costs so far were £400 for stage/audio equipment hire, £250 X 2 for headline bands. IB also wished to make a payment to 35 other musicians who had agreed to play at the festival. After discussion, we **agreed to a payment of £15 per head to each individual (Action IB).**
12. **Wellcome Trust funding request.** MC had been preparing a bid to source funding for the group from the Wellcome Trust. It was felt that the amount being requested (£125K over 5 years) would probably be considered too great an amount when compared to our groups annual turnover (Approx £35K). In the light of this view **MC would find out more about how we should approach this and prepare a bid for a smaller amount.**
13. **Awareness of HSP Group.** MC asked how we could get the group to be better known to those who were newly diagnosed with HSP. After discussion, it was agreed that the most productive route might be to get a list of those UK neurologists who would be confirming diagnoses (estimated to be about 30 individuals) and to then prepare suitable information for them to pass on to patients. **(AL to draw up a list).**
14. **2018 AGM feedback.** MC asked that we prepare a summary for the forthcoming AGM of what had been achieved in response to the topics raised in last years round table discussions. Progress so far:
- a) Web Site – draft view available
 - b) Mission Statement – Being developed (see item 2a above)
 - c) New Activities – maybe: Flying Scholarships; Potato Pants; Activities seem a bit southern based. Volunteers needed to take up more northerly opportunities. further thoughts?
 - d) Communication Channels - ??
 - e) Young People in Newsletter – (develop idea of Ambassadors?)
 - f) Research – developing criteria; ??
 - g) Lobbying -
 - h) Internet support -
 - i) Groups for Special Interests – discussed, resolves back to keeping people informed and maybe special interest table at AGM??
15. **Number of members receiving grants and the level of funding given.** MC raised concerns that there were apparent disparities with only a few members receiving grants and all for the maximum amount. Over time there had been smaller amounts applied for and given, and for various different things e.g. for FES assessment before it was part of NICE guidelines. Grants are publicised in every issue of the newsletter and on the web site. **We should review wording to try to “widen the scope” of applying.** No other action needed.
16. **Web Site.** AL had sent out an email late yesterday as he had received an update from Jenni about progress on the new web site. She has given a link to a draft of the new site and would like to get some high quality photos to populate the site. Would Trustees please have a look at the site and contribute any relevant photos.

17. **Update on PARC study. [Physical Activity for Rare Conditions].** The study is at the stage where they are looking at what should be measured in order to work out if particular activities benefit specific conditions. **AL will invite Gita to an AGM** (probably 2020) in order to report on the project.
18. **Update on NICE cannabis consultation.** AL was pleased to report that our representations had got HSP listed as one of the conditions to be considered. In addition it had been accepted that long term condition management was also an appropriate field to be considered.
19. **SPATAX 2019 conference – Sept 20 & 21, Nice.** AL was prepared to attend this Spasticity and Ataxia event. Trustees were asked to consider if we should provide funding to support the conference as well as the actual costs of attending. One or two other groups provided funding of about £1000 - £1500. It was agreed that we should provide funding this year.

MC suggested that he would circulate information from the SRCA Conference in Sheffield at which HSP SPG 7 is an item given by one of the doctors researching HSP SPG7
20. **EuroHSP board.** AL had been invited to join the board. He would be attending the next meeting in June to decide if he could take the task on. Trustees would be interested to find out his views after that meeting. AL would discuss the situation with Simon Hubbard to help form a common view.
21. **Virtual meetings** – did we get set up? (e-mail sent 17th July 2018). Various Trustees had got to the Virtual Lobby page. Others were now unsure if they had achieved that status. **AL will send reminder info.**
22. **Additional Trustee.** Stephanie Flower becoming a trustee again? (e-mail sent 28th Sept 2018). It was agreed that it would be appropriate to propose her as a candidate for election at the next AGM. Like other trustees there would be an obligation to attend management meetings.
23. AOB
 - a) **International Society of Neurologists meeting in Sheffield in May.** MC drew attention to this meeting and asked if the group should be represented.
 - b) IB reported that the group had been left a **bequest in the will of former Chairman David Pearce** who died last year. The amount left was a substantial one, estimated to be about £70,000. Details of the will were still being worked through as some of it was understood to consist of a property occupied by tenants, so there might well be a change to the final amount.
 - c) JM gave a brief report on the **Groups finances**, we had £46K in the bank accounts, with an outstanding commitment of £10K to the project at Exeter.

There being no further business, the meeting concluded at 17.15.