

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
1st September 2020, Start time 18:30

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Ian Bennett (IB), Mike Cain (MC), Mitesh Patel (MP), Neil Cuthbertson (NC).
Welcome to Neil – Neil was introduced to Trustees as a member who was considering joining the Trustees. His appearance in this meeting was to help him in that decision.
2. **Updates from Previous Meetings** – (16th June – no actions, 25th April – some actions)
 - TOR for newsletter & website committees – no progress
 - Letters to Scotland/Mary Bythel/Diana Baran – no progress. AL asked MC to respond to the Diana Baran letter.
 - Potato Pants Festival update. Ian stated his intention was to run a very small event – perhaps a single musician in a pub which would be broadcast on the web. This might allow a small amount to be collected for our funds.
3. **Review of policies – three are overdue to be reviewed:**
 - **Expenses** - Needs to be updated to reflect new trustee/committee structure, and to capture update on room hire and refreshment costs now being covered for meetings.
 - **Expenses Policy** JM Had updated the Expenses Policy and provided the following text:

“Expenses Policy

The Trustees give their time freely and at no cost to the HSP Support Group.
Out of pocket expenses MAY be claimed by members attending Trustee **meetings** ie
Travel by public transport at standard class at cost
Travel by car at 25p/mile, car park and toll charges
Food and drink purchase during the journey and the meeting
Accommodation by prior agreement

To attend the **AGM** Trustees MAY claim for an overnight stay if travelling there and back in one day would be too much for the individual.
Members may claim travel expenses to the AGM if they bring another member.
Out of pocket expenses may be claimed by **speakers invited** to HSP Group meetings by prior agreement.
Out of pocket expenses may be claimed by members asked to attend meetings to **represent HSP Group** by prior agreement.
Room hire and refreshment costs may be claimed by members organising local Group meetings.
Expense claims must be backed up by evidence of the expenditure and be submitted within 1 month.
Claims will be settled by direct bank transfers whenever possible”
 - After discussion the Trustees agreed this wording subject to the inclusion of the agreed values for meeting expenses.
JM undertook to update the document and send new draft out.
 - **Allocation of Funds** - Needs to better capture how we make decisions about funds. Needs updating to reflect the terms of reference for the committees, perhaps expenses needs to come out to avoid duplication. **JM undertook to update the document and send new draft to Adam.**
 - **Risk** - Might need a bit more structure, and perhaps we need to be stronger on the mitigation front?. **NC will update the document in line with the discussions we’ve had today.**
Website backup – Frequency of backup for new site not known. **DH will find out from Jenni Preston and report back.**
4. **Review proposed changes to Meetings committee terms of reference**
Meetings committee terms of reference. IB had reviewed the changes recommended by Hilary and Jane. The document met the needs of helping to provide a structure and some guidance for new meeting organisers. Various clarifications were suggested including the need for copies of minutes to be kept. **AL would discuss these with Hilary and Jane.**

5. Committee Reports:

Research Committee. MC submitted the following:

“The Research Subcommittee consists of Adam Lawrence, Mitesh Patel, Simon Hubbard, Siang Ing Lee (Ing), and Mike Cain

The subcommittee received three applications for support from clinical and academic institutions Rome, Exeter and Sheffield

As reported at the last trustee meeting these were all approved in part

Rome had asked for £10,000 and we agreed £2000 as they were looking for a biomarker and we hope to receive some benefit

Exeter applied for £60,000 over three years

after some debate, we agreed to fund £15,000 in the first year, and £15,000 in following years with the addition that if funds permit and fundraising helps, we can continue to fund.

Sheffield applied for £81,000 over 3.5 years

Again we offered the same conditions to Sheffield

Effectively, for Sheffield and Exeter we agreed that we would fund them at £15k per year for the remaining years if we raised sufficient funds to do so,

The discussion was to consider points of view and how we would take research forward in subsequent years when hopefully we would get new applicants. Different views were considered as we are a small charity.

Should we be expected to fund a complete PhD project or should we have funds available to meet credible requests from subsequent sources? Or Both??. Both had merit”

- No new applications had been received since.

We had not received a request for payment yet from Sheffield. **AL would follow this up so that we have a clearer idea of when payment might be made.**

AL would also follow up how we might support the Sheffield initiative re an HSP paediatric clinic.

- **Membership Committee.** MP had given the following report:

“I have taken over the role as Membership secretary from Ian, who will continue to publish the newsletter and distribute this to the members. John is continuing to help with management of the database.

We now have 357 members (from 339 in the previous report) and 99 consultants. This will be due to the fantastic updated website with easy online method of payment and the great success of the AGM in July. I am sure the new members have enjoyed the use of Zoom for meeting and to tune into presentations from health care professionals.

We continue to send out a leaflet and a membership card to each new member. The next newsletter will be in September 2020.”

- **Fundraising Committee.** Rachel Mortimer Holdsworth sent this report on 25/8/20:
- 3 year fundraising strategy to be drafted in the coming weeks
- Fundraising committee to meet (digitally) in Oct/Nov, agenda to include:
- Review of fundraising strategy
 - Agree roles and duties of fundraising committee and identify where other support is needed
 - Discuss next steps for progressing funding of 2 x phd's of £15,000 each per year for 3 more years (£90,000 in total)
- Other actions in coming weeks:
 - Easyfundraising to be added to the HSP website, and promoted in next newsletter
 - Amazonsmile to be set-up, and promoted in next newsletter”

- 6. **Feedback on AGM and subsequent digital events.** Trustees agreed that the approach had been a success with very similar number to our “live” AGMs. The AGM meeting and the subsequent presentations had generated 568 “views” which was encouraging. Not all views would have resulted in people seeing the whole item however. We had published two of the presentations on the Youtube channel, but we were still awaiting a version from the team at Exeter where a minor update was to be made. **AL would follow up within the next few weeks.**

7. **Future digital meetings update.** AL has now given Zoom training to the Meetings committee. There were still concerns as to how some of our organisers (or indeed members) would be able to participate but overall this is agreed to be worthwhile.
8. **Ian Marsden is a paracanoeist on the UK Paralympics team who has HSP, and an online video about him has been produced by Rare Disease UK.** Adam has contacted him and will see if there is synergy with the group.
9. **Post-graduate studies help.** Ing Siang Lee has been in contact with course leaders and we have the opportunity to get post-graduates to help with analysis as part of their studies
10. **Finances.** JM Provided the following update:
The state of finances is: We have £123,980.16 in the bank.

Sheffield University has not yet asked for the grant (£15,000) that we approved earlier in the year.

11. AOB

- **HSP “visiting card” production.** - AL says this has not happened yet – will pursue.
 - **Discussion on HSP Group “Rebranding’** A range of views were aired by Trustees and it was clear there was an appetite for updating both the groups Name and Logo to make it more appealing to a wider public. This topic will be taken forward via email discussion.
 - **Findacure** have been discussing registries that some successful conditions have formed with clinical involvement. From these discussions and the comments of Gita at the AGM, MC thinks our Group should represent most of the people in UK. AL asked MC to put something together that we could adopt.
 - **Video Clips.** Dr Channa had asked for two members to provide a short video which he could use in talks to med schools etc. MC had sent him video of Amber, Lily and Ian Marsden as well as his talk at Bridgewater Hall, but these were too long and two previous suggestion of possible members had not been forthcoming. It was raised at this meeting although with short notice there was still time to submit something. The deadline for participation now being tomorrow, Wednesday the 3rd, it was felt we had left it too late to submit.
 - **Safeguarding Policy** – IB would provide a copy of the recently revised FSDP charity’s policy for AL to consider.
12. **Face-to-face meetings discussions.** AL felt strongly that we should have a plan on how to return the Group to having face-to-face meetings for members. After considerable discussion it was agreed that we should not take any action about this until the end of the current Flu season was in sight. We should therefore discuss this in mid-January 2021 with a view to deciding about those meetings traditionally held in March and April.

We agreed that there would be no face-to-face group meetings before 28/2/21, and that AL agreed to share this news with Hilary & Jane, and in our next communications to members.

There being no further business, the meeting concluded at 20.35.