

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

23rd September 2022, Start time 19:00

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Mike Cain (MC), (Shanake Amarasinghe, Kolade Olaiya – observers).
Apologies: Emily Bell (EB)
2. **Introductions and hellos** – welcome to Shanake and Kolade.
AL Welcomed Shanake and Kolade to the meeting. He would be discussing with Trustees about possibly co-opting them as Trustees after the meeting.
3. **Previous Minutes** Version 1 of the 3rd April minutes had been circulated and were accepted as correct.
4. **Review of the digital AGM**
A brief discussion of the on-line approach concluded that for our size of meeting the present approach was a good one. Consideration should be given to the wording in our Constitution to reinforce this.
5. **Brief update on 8th October Group Social.**
Twenty three people were booked in for lunch on the day. This was considered sufficient to proceed with the meeting. AL commented that HSP Researchers were still being confirmed. It was not considered that the planned rail strike on that day would have a significant effect. We now expect over 40 people to attend).
6. **Quick summary of headlines/issues from each of the committees**
 - **Web Site, Membership, Research** – nothing to report. Web Site may hold a further meeting next month.
 - **Meetings** – Ian Bennett had stepped down from the committee. The welcome pack has now been completed. Face-to-face meetings were being held again.
 - **Fundraising** – Discussion were held about fundraising target. There were some doubts about the value of targets in the present situation. JM offer to follow up this at the next meeting.
7. **Should we have a member survey?.**
Possible topics and mechanisms were discussed. AL will produce a spreadsheet prototype for discussion.
8. **Review of recent consultants survey**
This had revealed a more complex picture than had been expected. There were 27 centres identified and 75 different consultants had been named. A discussion on how to offer this information concluded that there was insufficient consistency for us to publish it yet. We probably need to progress one step at a time until there is more clarity. Consultants will be invited to join HSPSG as Honorary members so that they get the regular and research newsletters. **MP** to contact them.
JM agreed to draft an item for the website to guide HSPers in approaching their GP for a neurological consultation.
9. **Specialist HSP centre set-up (a short update from MC)**
MC Had identified two centres which were nationally known. These were London Queens Square and Sheffield. Sheffield seems to be recognised as a Specialist HSP centre as patients going there can get travel costs paid. MC would contact London to see if we can get them also to move towards this situation.
10. **Third party/event insurance**
JM apologised this had not been done. He will do it on Monday. [Post meeting confirmation – this is now in effect]
11. **Member grant applications**
Since our last meeting there had been five applications. Four had been approved and one had been turned down. One which had been approved (for a cooker) had failed to

respond to both email and phone messages. It was agreed that there was no more we could reasonably do.

12. Finance update

As of 3/9/22 we had £139,673. We had paid £15K to Exeter University for the agreed research project. Long term we have a further £60K in committed research expenditure.

13. Young people with HSP study proposal from Tony Hart

After a brief discussion it was agreed that the group could support this initiative by offering appropriate members the opportunity to take part in the study when it goes ahead.

14. Updates to leaflets/business cards

Information on the cards and leaflets is out of date. Whilst it was agreed there are benefits in having something tangible for points of contact to pass to newly diagnosed people, there was no sensible way for us to distribute them to appropriate places. Indeed we still have boxes of the previous out-of-date ones unused. No action now – defer for future consideration.

15. Update from EuroHSP

AL, Zoom meeting held 8/9/22 – they are seeking action/funding across Europe to move the Rome study we funded forward:

- Cell models project – trial for SPG4
- Contributions will be sought from members organisations
- Agreed that funding similar to last round (£2K) will be supported by HSPGroup.

16. Any other business

MP thought that it was now appropriate for our Trustees (present and proposed) to have DBS checks done. After a short discussion this was agreed. It was also agreed that the cost (approx. £15pp) would be paid by the group.

There being no further business, the meeting concluded at 20.40.