

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

20th March 2025, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH), Estelle Marshall (EM), Helen Payne (HP), Michael Payne (MP), John Mason (JM), Mike Cain (MC)

Apologies: Mitesh Patel (MB), Juan Vazquez Ruiz (JR)

1. Introduction

AL welcomed attendees to the meeting.

2. AGM Planning.

- a) Venue. It was agreed that we would ask Penny and June to survey the Holiday Inn in Kenilworth and Millennium Point sites and we would be happy to go with their recommendation. The 26th of July was our agreed date and the venue availability for that date should be checked also.
- b) Speakers. AL was intending to have two speakers from UK research teams and possibly one other – perhaps from new volunteers (Aarush perhaps?).
- c) EM offered to host a short chair-based exercise session which was suitable for all. Accepted.
- d) Day outline. AL suggested that members arriving between 10 and 11 am, then running the AGM session before lunch with speakers in the afternoon. This was agreed.
- e) Trustees up for re-election were: DH, HP, MP, JM, JR. All present indicated they were prepared to stand again. AL would contact JR to check his stance.

3. Award nominations.

AL would produce an item for Newslink asking our members for nominations for our annual awards.

4. Policy Updates

JM/AL work on policy updates was still in progress.

AL also intended to provide an updated Risk Policy including risks associated with having to close the group.

5. Committees.

AL felt that there was a need to have a more focussed discussion, perhaps on Zoom about the committee structure.

6. Pippa Lee book.

AL had received a draft contract from Pippa, but a decision had been made to go with a much simplified agreement. AL would confirm this and proceed with the award of the first payment to Pippa. Estelle's offer of help has resulted in her being co-author.

NB Estelle is working on a separate booklet to help people with HSP to symptom manage. The aim is that this will be able to be accessed free electronically - possibly via a link on the website.

7. AOB

a) International HSP day – Oct 17th. Various opportunities were possible to publicise the condition along with international efforts: MC suggested involvement of medical neurology students, perhaps by offering a grant if they studied HSP; possibly we could involve other "high profile" members? (e.g. Gregor Anderson, Jack Long, Lily Rice, Ian Marsden)

b) Bank Accounts JM stated that monies in the bank accounts had been adjusted as follows: Current A/c now held £17K, and the Savings A/c held £140K.

c) Handover planning, JM requested that access to the membership Database be provided for Michael Payne in preparation for handover.

d) Outstanding Commitments. £30K was still outstanding for payment to Sheffield. AL agreed to discuss this with Channa and seek a resolution.

e) Research Payments. Cambridge: No invoice has been received and MC thought that Cambridge may have received funds from another source. JM said no payments had been made in the last 12 months and believed all was up-to-date.

Sheffield: It was thought that the student was off sick and research had not started in spite of our payment of £30K. AL to contact Channa to see what is the current position.

f) European Research Grant. AL stated that we had paid a total of €8500 so far and there were no further commitments.

g) Emailer - notice of Meetings and Membership Renewal. It was suggested that member Luke Scudder who had volunteered last year should be contacted to see if he was prepared to take this over, JM would follow up.

h) Online Payment Facility for Membership Renewals. JM suggested this might be a useful way of making the recruitment process easier. Stripe was suggested as possible system.

i) Research Institutes communications. AL would prepare a new Research Newsletter to keep in touch with these organisations.

k) PIP Changes. MC Has sought clarification of PIP from Liz Kendall MP (SoS at DWP) and my MP Lisa Nandy '**Does HSP diag mean no assessment unless need for further help initiated by person**'.

There being no further business, the meeting concluded at 20.30.