

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
16th January 2025, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH), Estelle Marshall (EM), Helen Payne (HP)
Michael Payne (MP)

Apologies: Mitesh Patel (MB), John Mason (JM), Mike Cain (MC)

1. Introduction

AL welcomed attendees to the meeting. He explained that both John Mason and Mike Cain were in hospital at the moment, so we had a reduced number attending.

2. Decisions needed.

a) Award nominations. AL asked for suggestions for recipients for awards at our 2025 AGM. No suggestions were made, with trustees feeling that there had not been any “stand out” events or candidates thus far, and certainly no recommendations from our members. AL would put a piece in the next Newslink asking for nominations.

b) Pippa Lee Booklet. AL reported that Pippa was well into the drafting of the booklet and wanted confirmation that we would support the publication. Trustees agreed to fund the effort and it was agreed that two payments, each of £1600 would be provided at the appropriate times.

3. Youth Support Volunteering.

AL reported he'd had approaches from two individuals (Aarush and Milan) who both wanted to help to support younger persons with HSP. It would be helpful if we could give such individuals a title which would describe what they did. Trustees agreed on the term “Youth Ambassadors” as appropriate. AL would go back and discuss how these offers could be developed.

4. Policy Updates

Trustees had indicated satisfaction with the initial set of policies, there was no need to update the wording. John Mason and AL would proceed with the process of refreshing these with new review dates etc.

After discussion it was agreed that the Mission Statement still matched the groups intentions and aspirations.

Other policies were pending, and now awaited John Mason and AL availability to sort out.

A similar situation applied to the Trustee Application for which required some modification.

After discussion it was agreed that one or two places which referred to “training” for trustees should use “guidance” instead.

The Risk Policy should be updated to include the risk of closure of the organisation which had been developed as a result of our situation around the last AGM.

5. AGM Planning.

Physical Meeting. Trustees present agreed that we should have a physical meeting this year. It was important to identify and book a venue so that plans and publicity could be developed. As the Tally Ho premises were no longer hosting events we would have to identify another location. AL would discuss with Penny Cohen, June Masding and Sian Ing Lee to see if suitable premises in the West Midlands area could be identified. The intention was to return to our “traditional” date around the end of July.

6. Committees

AL had developed a presentation describing the Committee structure. He hopes to produce it as a Zoom discussion and the load it onto the YouTube channel.

7. AOB

a) AL has now loaded the 3rd AGM presentation onto the YouTube channel.

b) MP stated we had now received £30,000 from the Joy Rainey Bequest. This is a sort of “interim” payment. There may be a further payment when the estate is eventually finalised.

c) Phil Bungay was arranging an event in Medway area at which charities may have a stall. AL would talk with Hilary Croydon and Jane Bennett to see if we could man such a stall.

There being no further business, the meeting concluded at 20.16.

Agreed by email as an accurate record on 13 February 2025.