

# HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

29th May 2024, Start time 19:00

## Minutes

**Attendees:** Adam Lawrence (AL), Dave Harris (DH), Mike Cain (MC), Juan Vasquez Ruiz (JV), Shanake Amarasinghe (SA), Mitesh Patel (MB),

**Apologies:** None

### 1. Decisions

- a) Emily Bell had informed Adam in the last two weeks that she is standing down from her Trusteeship with immediate effect due to pressure of work.
- b) AL wanted to use this meeting primarily to ensure we were prepared for the upcoming AGM SA stated that he would need more time to complete the financials and asked that the AGM be moved to a later date. After discussion it was agreed to re-schedule the meeting to Saturday 24<sup>th</sup> August. AL would notify members via a Newslink article and email as this was a change from the date published at our last AGM. Various suggestions were offered by trustees as to possible speakers.
- c) Newslink – Ian Bennett had told AL that he (Ian) intends the currently being produced issue to be the last one he will edit. The Group therefore need to find a new editor for future issues.
- d) AL asked that any persons offering to volunteer for the group should be put in touch with him

### 2. Sub Committees. –

#### **Membership Committee.**

MP stated that some memberships had lapsed as members felt they were not getting access to meetings any more. At present we had about 410 ordinary members and over 100 honorary members.

#### **Research Committee**

No Report

#### **Fundraising Committee**

No Report

#### **Website Committee**

No Report

#### **Meetings Committee**

Various points had been discussed and resolved in the meetings committee. MC brought some outstanding ones for Trustees to consider/ decide:

- a) The possibility of meeting specific email addresses being available such as [milford@hspgroup.org](mailto:milford@hspgroup.org). **AGREED** AL to request John Mason to set up suitable email addresses.
- b) Whether or not meeting organisers can be given the contact details of members in their area. Trustees felt that personal details should not be shared by the group without prior approval. Members sharing information among themselves was not an issue.
- c) Trustees **AGREED** to increasing the base cost for members attending a meeting to £7.50 per head. We would amend the wording of the Constitution to clarify that other necessary costs may also be reimburse by prior agreement of Trustees.
- d) Scattergram showing location of the membership membership was still awaited. AL would follow up with the individual he had previously discussed the matter with.
- e) Production of the HSP introductory leaflet – this had also not been actioned due to the lack of a volunteer to produce it. MC undertook to speak with individuals whom he thought might volunteer.

### 3. Finance Updates

SA gave a summary of income and expenditure as at the end of April:

Income £31K, Expenditure £39K, Cash in bank account stood at £118K.

**4. Secretary Updates.**

Four Grant Applications since last report in January. One Approved, one rejected – not a member.  
Thirty new contact forms over the same period  
Also a similar number of “Spam” type messages

**5. AOB.**

None

There being no further business, the meeting concluded at 20.10.