

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
8th May 2021, Start time 19:00

Minutes

- Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Ian Bennett (IB), Mike Cain (MC).
Apologies: Neil Cuthbertson (NC)
- AGM.** After a short discussion on the present Covid situation and the likely timings for the lifting of restrictions it was decided that it would be appropriate for the 2021 AGM (Saturday 3rd July) to be held as a virtual meeting rather than as a face-to-face meeting.

For this year it was agreed that voting would be conducted by both postal and email methods and would be completed in advance of the meeting. The results of the vote would be announced at the meeting.

A discussion on possible speakers was held and AL will follow up the suggestions made. It was felt that a similar format to the last AGM was appropriate with each speaker providing an on-line session on different dates.

IB stated his intention to stand down as a Trustee, all others present indicated that they were prepared to continue for the next year.

After a short discussion it was agreed to make the following awards for the year:

Fundraising: Estelle Marshall; Jade Bennett – both achieved great results during a difficult time.

Awareness: Jenni Preston – her excellent work on the new web site has proved very effective.
- Meetings.** Face-to-face meetings later in the year were discussed. It was agreed that where it was necessary to book venues in order to make meetings possible, organisers could do this and the Group were prepared to bear cancellation cost where these were unavoidable. We would not publicly announce dates of such meetings until we could be certain that the meeting could proceed and we could also publish any constraints which would be necessary. Our next decision date for this subject would be after the June 21st Covid de-restriction date.

IB raised the idea of running bi-monthly virtual meetings for our members. These would be open to the whole membership and not related to localities. After some consideration this idea was approved.
- Succession Planning.** AL noted that both DH and JM had said they intended to stand down when their present terms were completed in 2022.

AL would work to get a succession plan in place by the time of the 2022 AGM. Given the varied nature of some of the “minor” tasks currently undertaken (e.g. Charity Commission registration; Web Site hosting; Membership database) it would be sensible to deal separately with each one.
- Finances.** JM had provided a draft of the financial accounts. Various questions were raised and answered and there were no outstanding issues.

Recent discussion by email had concluded that the cap on grants to members should be raised to £1000. The meeting approved this change.

It was agreed that a current application should be approved and awarded the newly approved maximum amount. IB suggested that it would be beneficial to the Group if this grant could be attributed to the monies raised this year by the Potato Pants initiative. This suggestion was approved by Trustees.

AL would ask for updates on the recently funded projects for both Exeter and Sheffield.

6. Membership. Since the last report there have been 4 new group members.

Members who have not paid their standing orders in recent years are currently being chased to find out if they still wish to be members.

The membership summary produced by JM was noted as being good. JM can add other summary information to it if needed. A copy of the summary will be made each year for record tracking.

MP will update trustees and membership committee every month or two with a summary of new members.

The membership welcome letter will be modified to ask new members if they wish to have a follow up call from someone local.

7. Group Needs

Group Patrons. IB suggested that it may be worthwhile to ask those students who have benefitted from our sponsorship to consider becoming Patrons of the Group. He could see this providing the Group with further benefit in the future. There was general support for this idea.

AL would ask Olivia Rickman if she would like to become an honorary member rather than an ambassador.

Membership Support. AL's recent survey has highlighted areas where individuals felt that they did not have sufficient knowledge about aspects of their condition. After discussion, it was agreed that we should invite our honorary members to consider developing documents and/or presentations about each specific topic. AL would initiate this by contacting these specialists. We would then work out how best to develop these contributions into a consistent framework helpful to our members.

A further avenue discussed was to ask our Ambassadors to provide short videos about topics they were individually familiar with (e.g. selecting the right wheelchair). These could then also be made available to our members to help them.

8. AOB

- **Awareness Raising.** MC discussed the activities he was pursuing to increase awareness of the HSP group in various forums. AL said he was happy with these activities and didn't think there was any conflict with activities by other members.
- **Website/Database management.** JM felt it was time to formalise the Committee structure for management of these activities and it was suggested the committee be formed with DH/JM and Jenni Preston. DH would be designated as Chair.
- **Summaries of Meetings.** MC thought it would be a benefit to have summaries of informal meetings published so that all members could get that information. After a brief discussion it was agreed that if this was to happen then Summaries needed to be coordinated and batches sent to Jenni Preston for uploading to the web site so as to minimise her workload.
- AL to discuss with Jenni creating a members forum on the website rather than uploading summaries of Zoom meeting reports.

There being no further business, the meeting concluded at 21.25.