

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

16th June 2020, Start time 20:30

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Ian Bennett (IB), Mike Cain (MC), Mitesh Patel (MP).
2. **Minutes of Previous Meetings – (25/04/20).** Agreed as a true record.
3. **Web Site.** The web site development had been checked by Trustees and Jenni had included changes from all feedback. It was agreed that we can now go ahead and make the new site go live. The Trustees agree to offer Jenni a small gift (value up to £50) to recognise the hard work she had put in on the Group's behalf. **DH and AL to liaise with Jenni.**
4. **AGM / Awards –** As agreed we will now be holding the AGM as a Zoom meeting. The voting membership is about 300 people. We now need 5% of members to be quorate – so 17-20 members joining the meeting should be sufficient. **AL and IB will establish exact numbers and the the necessary quorum number. AL will hold another one or two further “test” meeting to encourage further members to attend.**

Nominations for this years Awards were:

Lily Rice - for Promoting Awareness of the Group;
Peter Bateman - for Fundraising for the Group;
Estelle Marshall - for work in promoting meetings among members.

After discussion, it was agreed that the awards for 2020 would be given to Lily Rice and Peter Bateman.

5. **Research Committee Recommendations.** AL stated that the three application for this round had all been considered using our assessment procedure and it was felt that the procedure had worked well. The initial Committee Recommendations had been as follows:
 - **Institute of Molecular Biology and Pathology (IBPM) (Rome)** - a single award of £2000.
 - **University of Exeter Medical School (Exeter)** - payment of £10K per year for four years.
 - **University of Sheffield, and Royal Hallamshire Hospital (Sheffield)** - payment of £10K per year for four years.

After further consideration, AL proposed that we should increase the payment to the Exeter and Sheffield bids to £15K for the first year. After discussion, the committee agreed these revised recommendations. All award letters and subsequent discussions must ensure that payments after the first year are understood to dependent on our receipt of donations and are not guaranteed.

6. **AOB** It was agreed to set up a further one or two test Zoom meetings for members to ensure best possible AGM attendance. **AL will arrange.**

There being no further business, the meeting concluded at 21.15.