

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

7th December 2021, Start time 19:30

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Mike Cain (MC).
Apologies:
2. **Previous Minutes** Version 0 of the minutes had been circulated on 26th of August and were accepted as correct.
3. **Trustee recruitment update.**
AL reported that he had had one on-line expression of interest, but nothing further yet. He has another individual to chat to which had come via another route.
4. **TOR for Website and Newsletter committees**
TOR for both the Web Site and Newlink Committees were needed. AL would forward to MC a document related to the scope of the Web Site Committee and MC was prepared to develop it into TOR for the Committee.
AL will check whether Jenni Preston is content with the ongoing web site maintenance situation.
5. **Finances overview/summary**
JM reported very few recent transactions. We had approximately £131K in the bank. There were currently two member grants “in the works”.
6. **Meetings – face to face.**
It was agreed that in the present uncertain situation it was appropriate to continue our present restrictions on face-to-face meetings and reconsider in the New Year.
7. **Headlines from Tom Wahlig**
The EuroHSP research prize has been awarded this year and had been thought to be a worthwhile exercise. All Trustees were happy for the group to continue to consider funding its proportion of this prize for future years.
8. **Website discussion**
After a wide ranging discussion about the Web Site (and other topics) it was agreed that it would be a sound approach to have the future Committee review different “sections” of the web site each year so that over time the site content was kept up-to-date.
9. **AOB**
 - a) There was a brief discussion about the merits of our joining Neurological Alliance – with us each agreeing to review this outside of the meeting.
 - b) After a discussion about the possibility of getting specialist HSP clinics set up, MC agreed to talk to Ataxia, with AL agreeing to talk further with them if a link can be established.

There being no further business, the meeting concluded at 20.55.