

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
29th June 2021, Start time 20:00

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Ian Bennett (IB).
Apologies: Neil Cuthbertson (NC), Mitesh Patel (MP), Mike Cain (MC).

AGM.

Business:

- AL has some slides ready for JM&DH, to review after the meeting.
- AL would like to discuss what MP will cover in the membership report.
- Details received from Meetings, Research and Fundraising committees.
- Awards: a video of Thanks received from Jenni Preston, IM says Jade will participate in the AGM and speak to the meeting.
- AL asked IB – as this will be your last AGM as a trustee do you want to say anything to members? IB will say a few words.

Presentations: Three have been booked in (Henry Houlden 17th July – HSP and 100k genomes project, Coralie Seary 31st July – falls and balance, Ray Owen 28th August – mindfulness and acceptance)

Once again it is very difficult to get Calvert Trust to agree to anything. AL hopes to get them in on 14th Aug to make it one every 2 weeks.

Voting.

A total of 77 votes had been received from members, this represents over 20% of the membership. Three additional, duplicated votes have been rejected.

Scrutiny: AL reported that the postal votes and electronic votes have both been independently scrutinised.

All votes received are from members and were made before 23:59 on 26/6/21.

There are six votes which fail to match exactly the records in the database:

- One postal voter used a postcode which is different from that recorded in the database
- Two electronic voters used e-mail addresses which are different from those recorded in the database
- For three voters (all electronic) the database suggests that they don't appear to have paid their 2021 subs yet

After discussion it was agreed that there was no reason to discount any of these votes. AL would therefore include all the votes in his report to the AGM.

Group Change of Name:

There are approximately the same number of people voting for Keep Current Name as there are for HSP UK (40% of votes each).

The vote on the proposed change of name was discussed, but it was agreed by trustees that although there was some appetite for change, there was no clear mandate to make a change at this time. It would perhaps be appropriate to put the leading choice to our next AGM as an either/or vote. In the mean time we could also try out the "HSP UK" leading choice for trial events where appropriate. We could take the opportunity to have anew logo design also trialled to see if it works.

2. **Research Grants.**

The pandemic has disrupted plans for the Research Teams, and our payments have been affected:

Sheffield have a person ready to go for this role to start in Sept/Oct. Sheffield University requires Channa to have more funds committed than the £15k first year payment (which he has not yet claimed). He is seeking further funds from other sources.

AL thinks that given we have had no further applicants for research grants in the last year we should make the second year payments to both Sheffield and Exeter at the £15k as they applied for. After discussion, it was agreed that we should make the payments at £15K, but only when the relevant work was about to commence.

3. Fundraising.

AL's sister, Rachel, had suggested the idea that the group collectively goes from Lands End to John O'Groats (i.e. about 1000 miles) by any means over a 10 week period. People could either decide for themselves how far they wish to go and add their distances to the total, or people could sponsor the group as a whole. We add up the total distance travelled by any member and see how long it takes us to get from one end to the other. Distance does not have to be actually on the route, it can be clocked up ANYWHERE. Travel can be by ANY means (wheelchair, walk, bike, mobility scooter, swimming – etc.) and perhaps members family/friends could do parts of the distance for them instead.

After consideration, trustees agreed that this idea should be pursued. In order to get it in place during the summer weather period, AL would take it to a Fundraising Committee meeting soon after the AGM to get the activity set up.

4. AOB

a) IB Stated that meetings had been planned to deliver the awards to Jenni Preston and Jade Bennett.

b) IB was planning an issue of Newslink for late summer. He'd need some more contributions from members.

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