

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

20th September 2023, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH) Shanake Amarasinge (SA), Juan Vazquez Emily Bell (EB), Mitesh Patel (MP).

Apologies: N/A.

1. Decisions

Small number of membership enquiries had been received from people within the Republic of Ireland. Trustees had discussed the situation by email and had agreed that it would be possible to offer membership to such persons providing that it was understood that there would be no entitlement to member grants, nor to voting rights at the Annual General Meetings.

2. Sub Committees. –

Membership Committee.

The map on the web site showing the distribution of members across the country was in need of refreshment, it now being some four or more years since it was last updated.

NB The map published would be a single image, giving a broad idea of membership distribution. As before, it would not indicate any detail specific to an individual member.

AL said there was a need to grow the membership. He would be pleased to receive suggestions as to ways in which this might be done.

Research Committee

A research committee meeting earlier in the year had recommended approval of the £15,000 research grant application received from Evan Reid at Cambridge late last year. Trustees had considered this and now agreed to approve this application. DH/AL to notify Evan Reid of the decision.

Fundraising Committee

AL had loaded some more recent fundraising articles onto the website to help in maintaining the currency of the information. AL requested that all members help to identify such stories so they could continue to be added in a timely fashion.

Website Committee

As noted above some more fundraising items had been loaded.

Since the last committee meeting several minor maintenance items had been fixed.

DH was planning to hold a further meeting of the website committee mainly to introduce member Phil Arnold (who had volunteered to do some of this work) to the other members of the committee. This was likely to be sometime in mid October.

Meetings Committee

AL was please to announce that Hilary had now indicated her readiness to resume working as Chair of the Meetings Committee.

3. Finance Updates

SA, gave a brief summary of our current financial status: the group currently has assets of £108K. Income so far this financial year was £15K, and outgoings committed so far were £32K, resulting in an operating deficit of some £17K.

4. Secretary Updates.

DH reported that 29 new contact messages have been received since the last trustee meeting on 18 May. As usual these covered a great variety of topics but all have been dealt with satisfactorily. This number might reflect a general increase in enquiries, but it too early yet to confirm such a trend.

Six member grants have been given over this same period. Five of these were for Calvert Trust Holidays, with one more being for equipment.

Post the AGM the Charity Commission Web Site had been updated with Trustee details.

5. AOB.

AL invited members to share any relevant activities:

EB mentioned her grandfather used a Baclofen pump, and was now part of a trial using a different drug. She will find out more detail and report back.

MC reported attending both Genetic Alliance meetings and Neurological Alliance meetings

AL intends to post more items on Social Media channels.

AL was going to attend EUROHsp meetings. He would find out how other countries went about recruiting their members.

AGM vs Physical meetings – AL felt balance was in favour of continuing on-line meetings for AGM, but working to increase number and location for other meetings for members.

Updated Leaflets/Credit Card. MC highlighted the need for these. We need an updated version for distribution to clinics and other locations.

Subcommittee Minutes Sharing MC suggested that minutes be shared amongst committees so that items do not “fall down the gaps”.

Information about exercise activities on prescription. (DH note – any help completing this point appreciated)

There being no further business, the meeting concluded at 20.15.