

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

20th January 2024, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH) Shanake Amarasinghe (SA), Mike Cain (MC)

Apologies: Emily Bell (EB), Mitesh Patel (MP) Juan Vasquez Ruiz (JV).

1. Decisions

Since the last meeting, DH has notified Dr Evan Reid about our approval of the £15,000 research grant. Payment will be made when we receive the request from Cambridge.

2. Sub Committees. –

Membership Committee.

No report this meeting. MC asked if new members could be notified directly of meetings due to occur in their area. After discussion, it was not felt appropriate to change the present methods of member notification eg, geographical mail out from membership database, listings of upcoming meetings on our web site and in Newslink.

Research Committee

AL explained that our membership of EuroHSP was leading us to participation in three different ways:

a) annual membership fee of €150,

b) a contribution to the Adolf Strumpell award at €400, and

c) a contribution towards a proposed research project which would be €4000 in the first year, with a further two years to complete the project.

Items a) & b) were approved and after a short discussion it was agreed that we should budget to pay for item c) at €4000 for each of the next three years, reserving the right to make adjustments as necessary as the project gets under way.

AL will write a description of our decision and approach for the records. AL will circulate the recently received information to the research committee, who will meet with the expectation of confirming that this is a good use of our funds.

Fundraising Committee

No update this meeting.

Website Committee

Mike Cain's suggestions about ease of donation have been followed up. We've improved some routes (less keystrokes), and are investigating other possibilities.

Phil Arnold has started to investigate how we might use a Wordpress "plug-in" to allow us to accept donations directly. We'll need to understand any ramifications re Gift Aid if we choose to go in this direction.

No further action taken on previous discussion about membership records with Hilary Croydon. Hilary had asked her correspondents but has had no response to the suggested idea/approach.

Meetings Committee

Committee due to meet tomorrow.

3. Finance Updates

As at 31 December 2023, HSP had a cash balance of £117k in the bank.

Total income in the financial year (1 May 23 -31 Dec 23): £25k. Made up of:

-Fund Raising Activities: £13k (including income from Jason Main's Everest Base Camp Trek)

-Donations and legacies: £7k

-Subscriptions: £5k

Total expenditure in the financial year (1 May 23 -31 Dec 23): £34k. Main driver of expenditure: £30k was research grant payments.

4. Secretary Updates.

One Grant Application since last Trustees meeting. Approved. We also successfully processed one for Sarah Murphy after a hiatus due to email problems.

Seven new contact forms over the same period

Also about five "Spam" type messages.

The Dog Sled challenge initiated by Emma Leivesley with Charity Challenge had not been funded to the required level. We will await further information from either party before taking any action.

5. AOB.

a) AL is going to follow up from Channa Hewamadduma's offer of a presentation in 2023. He will discuss with Channa and decide the best option, maybe this years AGM?

b) MC Asked if we had any information about Benevity (an Amex charitable arm??) Nothing known.

c) HSP Leaflet info. MC's attempts to produce one on-line had faltered due to not having appropriate sized logo. If MC would provide the technical info (Pixel count/format) AL will review the different files that he know of.

d) MC raised a question about Payments for cost of meetings. AL stated that he was happy for costs of up to £80-£100 to be considered in line with the expenses policy. He reinforced that these should be provided as estimates for approval before any meeting was confirmed. AL will write some guidelines for circulation around trustees before wider circulation.

e) Connections with other organisations – MC offered to take up this task of researching/establishing mutually beneficial arrangements.

f) DH would contact Ian Bennett and find out the current status re the help line and counselling.

g) AL hoped to be speaking with Prof Jon Marsden soon to get an offered update on their research.

h) Sidneys thesis has been approved and she has passed her MSc. AL will discuss sharing of the information with members.

i) AL had an email in connection with assessors seeking information about HSP when conducting PIP Assessments in the midlands and Wales. He will respond to see what information can easily be shared.

j) Ings reported that a project we helped find people to contribute has now reported. – AL hopes to share information on the website soon.

There being no further business, the meeting concluded at 20.35.