

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

21st January 2023, Start time 15:00

Minutes

Attendees: Adam Lawrence (AL), John Mason (JM), Dave Harris (DH) Shanake Amarasinge (SH), Juan Vazquez Ruiz (JV) (observer).

Apologies: Mike Cain (MC) (technical issues prevented participation), Mitesh Patel (MP), Emily Bell (EB).

Welcome to Juan – Adam welcomed Juan to the meeting. There were no questions from Trustees.

1. Agreement of /points from previous meeting

JM reported on status of Consultant Survey. Members had provided 45 new names – these had no email address. JM had written to the 45 and received 10 responses, of these eight had agreed to become Honorary Members and two had declined. No specific reason had been given, JM assumes pressure of work contributed. It was agreed that we should chase up non-responders later this year.

2. AGM 2023 – virtual or hybrid meeting? –

After a brief discussion it was agreed that we should not hire a room for 2023, but stay with the on-line meeting. I.e there would not be a face-to-face AGM.

3. AGM 2023 – voting as last year or more formally?

There was no reason to change arrangements made last year. It was felt the checking which we did to verify votes was appropriate and adequate. We agreed to consider promoting a local meeting in the area to help local members meet each other.

4. Tom Bell fundraising idea – charity of the year at his employer.

AL said the idea was to have the HSP Group put forward as a nominee for possible selection as “Charity of The Year” for the SkyBet/Flutter Entertainment group jointly with the MNDA. After discussion (which noted that MC had reservations about us being associated with a betting organisation) Trustees agreed that we should allow the nomination to be put forward.

5. Amazon smile – closure of service.

Amazon had sent notice that they were winding up this part of their organisation. As part of this they would provide the group with 6 months revenue.

6. Website committee update

a. Jenni Preston status – now in full time work. HSP web tasks will be scheduled when her time permits.

b. Items Completed: Document Manager page – updated; Committee Structure page – redesigned; Trustees page – updated; “News” section renamed “Notice Board”.

A new Section “Living with HSP” has been added:

- Before you Buy. New web page.
- I have HSP, What can I do? New web page
- How to approach your GP.

c. Mass emailing, database changes. JM reported that the TSO server limit on sending email had now been raised to 500 messages per hour.

d. Work in discussion: Improved access to Membership Application form on mobiles; further pages for the Living with HSP section.

7. Meetings committee update – updated welcome pack

The updated welcome pack had been sent to AL who will review it.

JM asked if there was information on which meetings are being pursued? We'd just heard about Hitchin, but were there others not yet confirmed? AL would ask Hilary.

8. Research committee update - one application received, slow progress

AL mentioned a project being proposed by Evan Read at Cambridge which might make an application. This was likely to be for project expenses rather than manpower.

JM had previously confirmed that as yet no monies had been paid to the Sheffield research project, despite several attempts to help them.

9. Childhood HSP research.

AL had information about a Study being planned by Tony Hart in Sheffield. The project needed to find young people to participate. At the moment they had identified one or two candidates, but more were needed. JV has about 9 or 10 possible contacts and needed responses from Tony/Emily in Sheffield to pass these on.

There will be a presentation of results on Wednesday 25th

10. Business cards/leaflets

It was agreed that we should now proceed with a reprint of the credit card size info card. The Web Site Committee agreed to take up the task. Ian Bennett may have the most up-to-date version. AL would contact Ian to get the most recent copy. It may be useful for the card to include a QR code for the web site address as well as the URL.

11. Other Chair activities

a) AL has given a presentation about HSP during early December at his place of work. The company had made a donation of £250 to us as a result.

b) HSP studies by Sidney and Jovana in Cardiff had got a good response from our members.

c) The European Reference Network has now published the HSP Patient Journey on the ERN web site. This has also generated a contribution of €200 in recognition of the work Adam had done in producing of the document.

d) The Reach volunteering web site has generated various contacts and appears to be a good source of new Trustee prospects.

12. Finance.

JM reported that we had funds of £125K at the moment.

We have still not received an invoice from Sheffield for their research project. We had received six Grant Applications from members and had disbursed just under £5K in response.

The handover to Shanake was proceeding, and it was expected that it would conclude when we have our Audit with the current Auditors this year. We would need to produce a letter from the Secretary to formalise the change of Signatory on the Band A/C.

There being no further business, the meeting concluded at 16.08.