

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP  
Registered Charity No. 1181539  
Trustees Meeting – [Online Meeting].  
22nd November 2023, Start time 19:00

**Minutes**

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

**1. Decisions**

Minutes from last meeting agreed – no changes needed.

**2. Sub Committees. –**

**Membership Committee.**

MP explained that we are only receiving a small number of new renewals. Some members have not renewed due to 1) lack of local meetings 2) change in diagnosis so no longer feel need to be part of the group 3) lack of information/engagement throughout the year.

This is an update on the meetings' committee sent by AL;

- Estelle has hosted a second meeting.
- Pip has organised one for Norwich on 18th November..
- Tom Bell has offered to run a meeting in Yorkshire.
- Jane has been supporting Phil Bungay's development of neuro cafes in Kent.
- Mike continues to try to establish a face to face meeting in Scotland.
- We're awaiting a new scattergram of members to finalise the revised Welcome Pack.
- Pip offered to help the Group with the HSP Cards and flyers as members ask for them at meetings

AL will help to develop a map of members and meetings on a scattergram.

**Research Committee**

No new applications since the last meeting

AL will check with DH about notifying Dr Evan Reid from the last meeting - recommended approval of the £15,000 research grant application received from Evan Reid at Cambridge late last year

4000 euros request to help with fundraising for research the first year. Initial idea is to fund the first year and decide future funding based on the update of research.

**Fundraising Committee**

Rocking horse for auction by Terry Duffy did not sell at reserve price. Will be sold on ebay/on his behalf.

**Website Committee**

Childhood Onset Page added to web site <https://hspgroup.org/childhood-onset-hsp/>

Phil Arnold has volunteered to help with the website.

Considered suggestion about Members area on web site from Hilary Croydon. Present stance is that effort required to develop/moderate/maintain a member – driven function would not be justified. We will see if something like the contact system messages would be sufficient to meet the need.

**Meetings Committee**

Committee Meeting last week, introduced Phil Arnold, we'll now start working out how best to use his skills. Need to work out who does what ie how Phil contributes.

### **3. Finance Updates**

Year to date deficit £10,000 – had £24000 in (£2500 Potato Pants, others are small contributions), £34000 (£30000 for funding for Sheffield, £4000 member grants)  
£115000 in the bank as of 11/11/23

### **4. Secretary Updates**

Three Grant Applications since last Trustees meeting. All approved. A couple awaiting Invoices before payment.

Nine new contact forms over the same period  
Also about 8 to ten “Spam” type messages

Rocking Horse gifted by Terry Duffy went to auction. No bid made.

### **5. AOB.**

Discussed the email from Dr Katherine, University of East Anglia, regarding the letter of support. MC was concerned that this research is not being driven from patients. JV and MP stated that there was no concerns as we are not needing to provide funding and this may allow members to be involved with research. Consensus agreement that we will write a letter of support.

MC asked about the charity challenge fee – SA will send a document to explain this further

We pay yearly for EuroHSP. We have contributed towards the prizes; approximately 400 euros. UK/France/Italy have largest HSP groups and have put in most towards the prizes. All present agreed that we will continue with this. Discussions about Germany becoming involved.

Student voice prize – Delilah has written about HSP after discussion with Adam and has been submitted.

Briefly discussed role of Ambassadors for HSP – Amber has previously been appointed. We need to specify the roles of the ambassador clearly as lack of output currently.

JV setting up a community for SPG3A – helped set up website with 40 families. Foundation in US doing translational research and trying 4 avenues to find a cure – drugs, genetic therapy (sites at Jackson laboratory, Trinity College, Chicago)

There being no further business, the meeting concluded at 2035