

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No.1109398
Committee Meeting – Coal Orchard Pub, Taunton, Somerset.
13th July 2018, Start time 11:30

Minutes

1. Attendees: Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mike Cain (MC)
Apologies: Della Brookman, Ian Bennett.

2. Execution of Documents.

- HSP Support Group - Constitution - signed by Chairman and Secretary
- Confidentiality Agreement - individual copies signed by those present. Copies have been sent to other Trustees for signature.
- Data Protection and Confidentiality Policy - signed by Chairman and Secretary
- HSP Support Group Expenses Policy - signed by Chairman and Secretary
- HSP Support Group Use and Allocation of Funds - signed by Chairman and Secretary
- HSP Support Group Risk Management Policy - signed by Chairman and Secretary

Additionally, the Charity Commission Trustee Eligibility Declaration form was completed by those present. This would be circulated to other Trustees for signature after the meeting.

3. New Membership Form

This was a work in progress between Ian and John. For Cash Renewals, about 20 out of the total of 60 had been returned with another 20 or so being collected at the AGM using the new form. To complete this activity John needs to contact about 50 payees.

John has a secure mechanism for collection the information via a web form which he would recommend we use. This is designed so as to exclude the possibility of malware being introduced into our systems via the form.

It was agreed that the simplest membership form should be used with only basic data being collected.

The form should request simple information identifying the applicants connection with HSP:

- I have HSP
- I am a carer for someone with HSP
- Someone I know has HSP
- I have an interest in HSP
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4. 2019 AGM

The Tally Ho venue was considered to be suitable for our needs and we should ask for it to be booked again, possibly aiming for a date nearer to mid-June.

Della had run an on-line questionnaire which had showed that "other commitments" was the most common reason given by people who had not attended. This was consistent with the reasons given in Apologies prior to the AGM.

There was broad agreement that there should be about two speakers at the event. There would also be room for an organisation like Coloplast to give a short introduction early in the day to promote interest in their attendance over the rest of the day.

Time was spent discussing how the Group could provide support for younger members. After a wide ranging set of ideas including individually organised multi-member trips to national attractions and coach trips out from the AGM it was agreed that due to the wide geographical dispersion of members and the high costs of travel we were unable to find a single, affordable mechanism which would be both fair and beneficial to members. Agreed to keep the topic live in case other ideas emerged.

5. Topics from AGM Group Discussions

Several strong themes had arisen from these discussions:

Area	Details	Action
Website	Better information: Pointers to other sites/locations, more about specific types of HSP/people, advice/information on various issues. Sharing stories from members about what they have done. Fact sheets for different topics. Research information. Young people section. Make sure information is relevant and focussed.	Take ideas forward into new web site.
Mission statement	Having a mission statement helps make our story stronger	Need to develop - thoughts so far: Reducing Isolation / Sharing Ideas
Young trustee	Have a young person on the committee	No volunteer - need to develop? See below table
New activities	Fund-raising activities – e.g. coffee morning/HSP day. Trips/activities for members, especially young members and isolated members.	Discussed elsewhere in meeting
Links with others/net working	Create a network of links with other relevant organisations to improve awareness, share information, share tools. Might be charities, research networks, relevant organisations/individuals. Networks might cover specific aspects. Consider hosting network meetings/conferences	Links on Web Pages
Communication channels	Develop non-social-media channels for people to talk. Topics could cover: young people, equipment advice/trading, general chat, etc.	Need for forum moderation / curation. DEFER
Newsletter	Have a section by/for young members	Need a young Trustee - see above
Fundraising	Have specific projects and seek funding from trusts etc. Define a template/process so this is easier in the future	Need for fundraising committee. See more detail below table
Promoting our activities	Better publicity around our fund-raising, positive news stories, activities, things we have funded. Make it easier for people to donate. Publicity around our meetings and other events.	Agreed - integrate with other activities
Promoting HSP	Famous people with HSP, links with specific people/ places/activities/items – media friendly	Agreed- integrate with other activities
Research	Being clear about what research we would support. Making information about existing research more accessible. Develop ideas for potential research projects	Could follow from fundraising definitions. Classify: <ul style="list-style-type: none"> • Immediate Relief • Mid term drugs repurpose • Blue Sky
Lobbying	Raising awareness of HSP and associated issues with: MPs/Local authorities/transport bodies/companies	Wider than just HSP - DEFER
Non-internet support	Ensure that we're supporting those who don't have access to internet. Could consider funding internet access for these people?	DEFER

Young Trustee: It was suggested that we publicise this by means of invitations in the Newsletter and at meetings. “We think the HSP Support Group needs to better represent the views of younger people with the condition. We would like members in the age range 18 to 30 to consider becoming a Trustee so that they could put those views directly into our decision making. We would be happy to discuss what might be involved with anyone who has an interest - please feel free to talk with any Trustee to find out more.”

Fundraising: It was agreed that we should create a set of objectives/purposes to “frame” fundraising activities. This would be used to focus possible research activities which in turn would lead to the development of funding targets.

6. AOB

It was agreed to defer the following AOB items listed in Adams pre meeting email until another meeting;

- Euro HSP meeting in November
- Update to website
- Update to constitution
- Update to membership database
- Genetic Alliance AGM in September

- Holding virtual meetings - Adam will arrange a trial event so we can assess the practicability of it within the limits of our systems/ expertise.

There being no further business, the meeting concluded at 16.20.