

# HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

26th January 2021, Start time 19:00

## Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Ian Bennett (IB), Mitesh Patel (MP), Neil Cuthbertson (NC).  
**Apologies:** Mike Cain (MC)
2. **Previous Meetings – (1<sup>st</sup> September)** The Trustees agreed that the minutes were a true record of the meeting.
3. **Future Meetings.** The Coronavirus situation was likely to continue for several months before public meetings would be possible. There was no certainty at all about dates when restrictions will be modified/relaxed. In these circumstances the Trustees decided:
  - a) to defer any decision/action about the 2021 AGM until 1<sup>st</sup> May.
  - b) not to hold any local meetings in the near term and revisit that decision on 1<sup>st</sup> May.Adam will start to consider what speakers we might invite from May onwards when it may be clearer whether a live or video AGM meeting will be appropriate.
4. **Review of policies:**
  - **Expenses:** Approved by Trustees.
  - **Risk:** Approved by Trustees.
  - **Code of Conduct:** Approved by Trustees.
  - **Conflict of Interests:** NC had circulated an annotated version with changes suggested by JM. After consideration, the updated version was Approved by Trustees.
  - **Gifts:** Trustees discussed the policy wording and agreed that the monetary value limit should be set at £50. Subject to this change being made this policy was Approved by Trustees.
  - **Safeguarding:** After discussion various key points were noted:
    - our activities are mainly within our membership
    - our members are not abnormally vulnerable and are treated equally within our activities
    - we do not have “external customers”
    - we need to protect people from harm and abuse within our activities
    - we cannot change actions outside of our scope of activities
    - we can advise members where support might be found.

It was agreed that IB would provide a draft document for us based on a version from FSDP Charity. AL would then assist to provide a version for Trustees to consider.
5. **Storage and Control of Documents:** JM stated that the group has a number of documents such as Policies which define what the Group does. These documents are revised regularly and the latest versions are posted to the website where they can be seen by the public. These documents should be controlled ie there should be a procedure for reviewing, editing and publishing so that:
  - a) The latest version is revised
  - b) The revisions are approved by the Trustees
  - c) Documents posted to the website have a consistent formatThe principles were accepted by Trustees. JM offered to produce a document defining these points and volunteered to act as Document Controller.
6. **Group Name Change:** It was agreed that the three most popular suggested names be put to the AGM together with the option of “No Change”. We would then proceed based on the outcome of that vote.

7. **Electronic/Postal voting:** AL suggested that we should try and widen the voting base for our AGM by means of electronic and/or postal voting. This would allow people who were unable to travel to the AGM a chance to participate. The addition of postal voting would allow those who were not electronically connected to take part also. AL agreed to find the likely costs a challenges and report back to the next meeting.

## 8. **Committee Reports:**

### **Membership**

The group continue to grow, with new members every week. We now have 374 active members (from 357 in the last report) and 80 honorary members, with people joining from across the UK. With the ongoing COVID-19 pandemic, being a member of the group has helped with associated challenges but also allowed a new way to communicate, with our online AGM and other online meetings.

We have been pleased to have had students join the group and hope that this is another avenue that will allow the group to open up to new opportunities.

### **Fundraising**

- An enquiry was made in November to 'Lifearc' <https://www.lifearc.org/> for grant funding for a PhD student at Exeter University. We received a positive response in early December, and are waiting further information.
- The pandemic has resulted in a significant drop of member led fundraising activities. Until such a time that in-person activities, mass-participation events, and sponsorship activities can restart, we do not expect to see this this aspect of fundraising pick-up.
- However, small amounts have come in through Amazonsmile, Easyfundraising, and recycling for good causes.

The year ahead:

- 3 year fundraising strategy to be drafted
- Further grant applications to fund phd students to be explored and made
- Charity ballot for London Marathon 2022 to be entered. The cost is £370+vat, payable only if we are successful in the ballot. If we are successful, direct fundraising to cover the entry fee will be sought and secured, and we will publicise that we are looking for a runner
- Identification of future opportunities for member activities that can help raise funds, for such a time that the impact of the pandemic is less severe

### **Research**

- Since the last trustee meeting the committee has focused on revising the research grant application form. When we were reviewing the applications received in 2020 there were a few areas where we felt the form could do with improving. We have changed the questions that we ask, and given a bit more focus on how we would like applications to be presented. The form is ready for any applications received.
- No grant applications were received in the period up to 31<sup>st</sup> December 2020, and the current window is for applications up to 31<sup>st</sup> May 2021 for decisions to be made before 1<sup>st</sup> September 2021.
- Adam attended a Euro HSP meeting about setting up a scientific board and looking at what sort of project might be favoured at a European level. This discussion is still very much in the early stages. For context, there are five HSP groups in Europe funding projects into HSP. The Tom Wahlig Foundation (Germany) funds projects up to about €50k per year, The French HSP group – ASL – funds projects up to around €40k per year, The Italian HSP group – ViPS – funds projects up to about €30k per year, and the recently formed Austrian HSP group – Stopp HSP – funds projects up to around €10k. We are the other group! It means that in 2020 these groups funded about €150k of projects.

### **Meetings**

- Since our last report in September 2020 Gary Cliffe has resigned from the committee because of other commitments. However, Kevin Mills, Cath Ward and Joseph Mills have joined the committee. One other prospective meeting organiser has been invited to join but has declined, as she prefers to make progress with setting up a meeting first.
- The committee's Terms of Reference have been reviewed and finalised by the Trustees.

- The Welcome Pack for Meeting Organisers has been finalised and is with Adam Lawrence for the addition of a dynamic contents list. It will then be posted in paper form and also emailed (to provide choice) to the four prospective meeting organisers so that they can begin to prepare to run face to face meetings when it becomes possible to do so. The committee has agreed the wording of a letter/email to accompany it.
  - Zoom meetings have been held by members of the committee.
  - Two, organised by Jane Bennett and by June Masding and Penny Cohen, were deliberately small scale to test how the meetings would work for the local members concerned.
  - Another, run by Ian Bennett, was publicised on the Unite and UK HSP's Facebook groups and was open to all. It included a presentation and quiz, as well as the opportunity for members to socialise. A further large scale meeting was purely social.
  - A meeting was organised by Mike Cain, for those in Scotland only, as its objective was to bring people in Scotland together in the hope that someone there would take on running zoom and, eventually, face to face meetings. The people attending agreed to set up a WhatsApp group and Mike Cain has arranged a further zoom meeting for Scotland in February 2021. Joseph Mills has now offered to run that zoom meeting.
  - Ian Bennett and Adam Lawrence hosted a zoom meeting on 25th December, having in mind those who might be alone on Christmas Day. The response was lower than expected.
  - Reports of some, at least, of these meetings have been provided and sent to Debbie Orme for transmission to Ian Bennett for the Newslink and Jenni Preston for the website. It is hoped that all meetings will be reported so that the meetings the Group provides are visible and people will be encouraged to attend them and also to set up new ones.
  - The value of zoom meetings is referenced in the Welcome Pack, where accounts of two different meetings can be found, but the committee feels that additional training would be helpful.
  - This would support an increase in the number of zoom meetings and would assist new meeting organisers in assessing the level and location of interest in future face to face meetings. It is hoped to combine a short, written document(s) with a YouTube video clip. One possibility is to have three separate sections/documents: Setting up a meeting through the Group; Basic Zoom Hosting; and Advanced Zoom Hosting Features.
  - As indicated, four members of the Group have expressed interest in setting up meetings in their areas. These are Scotland, South Wales, Sheffield and Nottingham and, judging from the scattergram of members and existing meetings, these are all areas where there is a need. In addition, Ian Bennett plans to set one up in Bournemouth.
  - The committee held a second meeting at which Hilary Croydon stood down as Chair. No one came forward to fulfil the role and it was suggested the committee could do it together. This has yet to be resolved.
- The committee had a wide ranging discussion. It was agreed that all meeting organisers must be members of the HSP Support Group and that, for safeguarding reasons, a committee member, Trustee or other trusted member of the Group should attend the first meeting set up by a new meeting organiser.
- Ian Bennett plans to hold monthly zoom meetings for people across the country. It is hoped that new meeting organisers may emerge and new meetings develop from this.
- It was felt that the meetings page of the website could be developed further and possible options were put forward.

AL asked IB to think if he could suggest another member to take up the Chair role on this Committee.

**9. Genesis of Website and Newsletter committees.** Agreed to Defer to next meeting

**10. Financial Update - end of third quarter 2020-21 for HSP Support Group.**

A total of £6880 has now been raised to date through donations including £769 claimed back through Gift Aid for subscriptions and donations not made through Just Giving. 4 donations over £200 each have been made through Just Giving as well as several smaller ones. Neil Brear donated £300 raised by his company. Hilary Croydon and Jane Bennett with Rachel Mortimer's help have raised £46 by collecting 2kg of used stamps and small coins through Recycling for Good Causes.

One grant to Christine Leek for £750 has been given. The only other expenditure has been to Just Giving to whom we pay a monthly fee of £18. Sheffield University has been in touch with us regarding the funding grant but have not yet issued an invoice.

We have on 25th January 2021 a balance of £127,227 in the bank.

**11. Raising Awareness.** JM had noted MC's efforts in attending and also setting up a variety of meetings and web events which together were raising awareness of the group in various circles. Was there more we could do to support MC in the these activities?

**12. Brief update on offers of help received**

AL had circulated the video produced by Yuquian Ye (Yuqi) summarising the AGM. This is now available via our web site.

Another volunteer (Remi) has stepped up to offer to produce a "patient friendly" leaflet which will contain information about the condition and the types of treatment which can be helpful.

**13. AOB**

- IB made a request for contributions for the next lissue of Newslink

There being no further business, the meeting concluded at 20.50.