

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No.1109398

Committee Meeting – Winchester Hotel, Winchester, Hants.

27th January 2018, Start time 14:30

Minutes

1. Attendees: Adam Lawrence (AL), John Mason (JM), Ian Benett (IB), Mike Cain (MC)

Apologies: Dave Harris, Della Brookman, Simon Hubbard, Stephanie Flower

2. Minutes of previous meeting: The minutes of the Warminster meeting on 9th Sept 2017 were agreed as being accurate. AL signed a copy of the minutes for the records.

3. Matters Arising: It was agreed that all the matters arising would be covered under the agenda headings.

4. Updating the Constitution

JM Had reviewed the Charity Commission website and selected the most appropriate model for the revised constitution for the group. The different sections of the constitution were discussed, and a number of changes and adjustments were suggested:

- No changes needed for the proposed objects
- The draft clauses for powers and liability were agreed
- It was agreed that the minimum number of trustees would be 3, and the maximum 10.
- It was agreed that voting members of the group would be limited to adult individuals
- Clause 9 (6) was to be expanded to include both associate members and family members
- It was agreed that the constitution should allow proxy, postal and electronic voting
- It was decided that general meetings would be quorate with 5% of membership present
- It was agreed that matters would be passed by a majority of votes cast by those present*
- A process is needed to define how new trustees can be/are put forward for nomination
- It was agreed that Clause 18 would be used to set up committees to manage the group

* Post meeting note: Following review of draft minutes, voting to put in the revised constitution as “a majority of votes cast by those present and eligible to vote”. This has the effect of counting abstainers as votes against the matter.

Actions:

- JM to update draft constitution in line with the discussion
- AL to draft an initial committee structure
- AL to draft a letter explaining the changes to be included with the AGM documentation

An initial list of committees was discussed: Membership, Meetings, Research, Helpline, Newsletter, Website, Fundraising

• Members and voting

This issue was discussed. Anyone with an individual membership would be entitled to one vote on matters at general meetings. It was agreed that voting cards would be prepared for the AGM and those would be issued to voting members on arrival.

Matters would be passed by raising these cards and counting the number of votes for and against each matter.

- Committee/Trustee confirmation

AL to discuss with existing committee members how they see themselves fitting within the new committee structure.

It was discussed that having definition to the committees might encourage more people to help take an active part in the running of the group.

5. Policies & Guidelines.

Draft policies for Risk, Funds, Expenses and Regional Meeting Organisers were put forward and agreed at the meeting. These policies form the first policies of the group, and will be put on the website.

The data protection policy was no further developed than in earlier e-mail correspondence, and this policy required further work before being agreed. AL to action. It was agreed that regional meeting organisers are not expected to have lists of members local to their area, and meeting notifications would be arranged through the membership database.

It was agreed that the best approach would be to get all members to give their consent for us to hold and use their data, as described in the data protection policy. It was agreed that this would be best achieved by updating the membership form to get all of the necessary consents. It was suggested that all members would be asked to re-complete an application form, which would update their details and gain consent at the same time.

6. AGM 2018

- Speakers

AL reported that Rebecca Schule had agreed to talk at the AGM.

IB reported that Pat Reed had agreed to give a 10-15minute talk on caring.

IB would also ask Jumbulance if they would be prepared to give a talk.

- Discussions

It was agreed that a discussion would be needed with members on groups for kids and/or those with complex HSP. AL to draft and distribute the main issues to be captured by these discussions to the committee, and then to lead these discussions at the AGM.

- Suppliers & Others

IB noted that Flexyfoot and Coloplast had agreed to be at the AGM.

AL would ask June and Penny to ask people on their local list of contacts/suppliers to see if others would be interested in attending in the other room. It was agreed that a local mobility specialist would be a useful supplier to have present.

IB would also ask Terry Duffy if he would like to set up a stall.

7. Members Questionnaire

AL had drafted a questionnaire to send round to members. It was agreed that a final version of this would be sent round with the updated application form which would be used to gain personal data consents.

8. Grant Applications & Research Funding

- Current application

The current grant application was discussed. The application is from Professor Mimoun Azzouz at the University of Sheffield, for £10,000, to “Design and evaluate therapeutic vectors for SPG15, testing options in pre-clinical trials”. The project is expected to be a 2 year project costing £224k, of which £109k has already been raised.

It was felt that this application may be of limited benefit to members, and a response would be written to Professor Azzouz to seek clarification on how the work has the potential to help members with other forms of HSP. A decision would be made after the further information is received.

- General direction for support?

MC had prepared a draft of a document to help the decision making process for research grant applications. It was agreed that this type of approach was not beneficial at the moment, and that decisions would be made on the merits of each application as received.

It was agreed that there was no desire to get a general direction for supporting research within the group at this time.

9. Website

Jenni Preston had made good progress on drafting out a new website for the group, details of which had been circulated. It was agreed that the work Jenni had done was excellent.

Several comments were made and AL will feed these back to Jenni, including having randomised photos, a donate button, pages for fundraising, polices and supporting research as well as a link/page for Potato Pants festival.

IB will seek photos and stories from members which could be used on the website.

10. Rare Disease Day activities

This was discussed briefly. A couple of people on the committee had received an e-mail from NIHR Cambridge Biomedical Research Centre (BRC) who are organising a rare disease patient day at Friends Meeting House London on 21st March. MC agreed to go and represent the group.

11. A Patron for the Group?

E-mail discussion prior to the meeting had considered if Tom Fletcher would be a suitable patron for the group as he had worked with Lily Rice and Archie Blomfield before Christmas, both of which are children with HSP. There was no strong views on what we would expect a patron to do for us. IB is in contact with Tom Fletchers management team about a contribution for the newsletter.

12. AOB

There were no items for any other business.

13. Next Meeting

AL suggested that the next committee meeting would most likely be in May.

The meeting closed at 17:00.