

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

25th April 2020, Start time 13:00

Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Ian Bennett (IB), Mike Cain (MC), Mitesh Patel (MP).

2. **Minutes of Previous Meetings** – (15/02/20, 02/04/20).

3. **Outstanding Items from previous meetings:**
(16/02/19)

12 Wellcome Trust funding request. MC had been preparing a bid to source funding for the group from the Wellcome Trust. It was felt that the amount being requested (£125K over 5 years) would probably be considered too great an amount when compared to our groups annual turnover (Approx £35K). In the light of this view MC would find out more about how we should approach this and prepare a bid for a smaller amount.

This item will be passed to the Fundraising Committee.

13 Awareness of HSP Group. MC asked how we could get the group to be better known to those who were newly diagnosed with HSP. After discussion, it was agreed that the most productive route might be to get a list of those UK neurologists who would be confirming diagnoses (estimated to be about 30 individuals) and to then prepare suitable information for them to pass on to patients. (AL to draw up a list).

Adam presented a spreadsheet with some 47 identified HSP specialists. After discussion it was agreed that the appropriate way to contact these was to use Mitesh's NHS email account.

AL to prepare suitable introductory message, MP to send to specialists.

(15/02/20)

Dave Pearce bequest. David first joined the Committee as Secretary in September 1999 and later was our group's Chairman for several years until he stood down in 2008. He has left the group a bequest in his will which amounts to just under £87K. This amount has now been paid to the group by the Executors.

• **Calvert Trust proposal.** IB had known David well having spoken with him many times over the years and believes that it would be appropriate for the group to use some of the bequest to help some of our members to attend the Calvert Trust, which David had found hugely beneficial. He also thought that a significant amount should be used to support Research into the condition.

After discussion and consideration by the Trustees, **it was agreed that £10K should be set aside** to allow the group to provide half of the cost of Calvert Trust holidays for members in memory of David. Such support would only be given to any member once in any two year period.

IB Had contacted the Calvert Trust and they were enthusiastic and receptive to members attending on such a basis.

• **Awards for the longer term.** It was agreed that the Group would establish two awards each year in Davids name. These would consist of a cash award of £100, plus a "trophy" style item to be presented at the AGM. The awards would be for the years outstanding fundraiser and for the individual who had had the greatest effect in promoting awareness of the condition.

AL would include a note asking for nominations in his Newslink column.

Website. The demonstration web site developed by Jenni Preston has been well received with a variety of suggestions as to further information and possibilities. DH should contact Jenni and ask her to go ahead with further work to "flesh out" the design to accommodate much of the information on the existing site. We have not found any other members with blogs other than Adam, and only one or two photos have been sent to Jenni.

In the light of this situation it was agreed that the HSP group should fund access to resources (e.g. stock photo sites) so that Jenni could select more material to populate the site. The meeting very much wanted to be able to launch the site early in June 2020, but recognised that Jenni had to prioritise what she did as web site work was her livelihood. The meeting agreed to offer Jenni

payment to allow her to prioritise the groups work alongside her commercial clients to get this task done. DH to discuss these items with Jenni.

DH has contacted Jenni and she was due to undertake work to complete the transition to the new web site from mid-March 2020. Furthermore, Jenni is happy to do this at no cost to HSP group.

DH to follow up with Jenni to establish present progress.

(02/04/20)

AGM 2020 - Date 4th July.

We had agreed in previous email discussions that we would not postpone the AGM immediately. It would probably be appropriate to take that decision within the next month. We had contacted the charity commission and asked them if a delay to our AGM beyond the 15 months limit established in our Constitution would cause any difficulties from their point of view. Their answer was that they would not see any problem in our doing this as long as we made a formal record of our decision to do so as the present government guidance supported such action. **AL to decide action by end of April**

See further information in this Agenda, point 7 below.

Newslink. IB intends to produce the next issue of news link in May. As yet he had very limited material to include in the issue. Adam was hoping to produce some material in time for that issue. It was agreed that it is appropriate for Ian to put out a message to members asking for contributions via email. **John/Ian to action asap.**

Ian suggested that we could reserve the Front Page of this issue to publish details of the David Pearce bequest to the group and to lay out the initial things we have agreed to do with the money (previous minutes refer).

AL and IB to liaise on content and information about AGM.

4. Agreeing TOR for the four committees.

The Terms Of Reference Documents for the following committees had been circulated and discussed by email and were now agreed:

- **Membership Committee** – initial members: JM, IB, MP
- **Research Committee** – initial members: MC, AL, Simon Hubbard, MP, Siang Ing Lee
- **Fundraising Committee** – initial members: AL, IB
- **Meetings Committee** – initial members: IB, MC

5. Della Brookman's offer of becoming a trustee.

Agreed it was appropriate to invite as a member of Meetings Committee. **AL to action.**

6. Asking Carina Thurgood to become a trustee.

Agreed it was appropriate to invite as a member of Fundraising Committee. **AL to action.**

7. AGM

After discussion the following points were agreed: We would not have a physical AGM in the foreseeable future. Now that we have a clearer idea of the effectiveness of online meetings it was agreed that we should hold the "business" AGM on 4th July as planned, but hold it as an online meeting. We would need to set up a "test" meeting in the interim to ensure enough members could achieve access.

AI/IB to co-operate on this. AL will change Tally Ho booking to 2021.

8. Finalising the committees.

The first four Committees have now been set up (item 4 above refers). After discussion we believe that there is no need for a separate Helpline Committee. The task could be managed within the terms of the Membership Committee, which should be modified to include such activities. **AL to update.** Other TOR needed were:

- **Newsletter Committee** – initial members IB, AL
- **Website (& Social Media) Committee** – DH, AL, JM

9. Recent research grant applications

- **Institute of Molecular Biology and Pathology (IBPM) (Rome)** Application received, HSP Group process followed, initial assessment completed by Research Cttee members, will be progressed by Research Cttee.

- **University of Exeter Medical School (Exeter)** HSP Group process sent out 8/3/20. Nothing yet received formally.
 - **University of Sheffield, and Royal Hallamshire Hospital (Sheffield)** Application received within last day, HSP Group process followed, assessment will start asap.
- 10. HSP Database and Rare Disease registries within NHS England.**
After consideration it was agreed that we, as a members association, do not have a remit to collect clinical information, and will not for now become involved in this activity. AL may discuss further with Henry Houlden in due course.
- 11. Scottish Government management of HSP in Scotland**
MC states that Scotland has HSP lumped with ATAXIA and they quote an incidence which is an international figure ranging from 1/100,000 to 9/100,000. There are four Neurology Centres (Dundee, Aberdeen, Edinburgh and Glasgow). There is also a Scottish National Committee of Neurologists. **AL will send a letter to the Committee to find a good contact point for us.**
- 12. Potato Pants**
IB reports that the warm up event on June 27th will be cancelled and the Festival itself on August 15th is unlikely to take place. He may arrange an online festival – many of the bands were already doing online sets – but this was unlikely to make any money. He was considering doing it in support of the NHS, this would generate publicity for the Group, the primary goal being developing awareness.
- 13. Finance**
JM provided an Income and Expenditure report and Balance Sheet. Income had been bolstered this year by the receipt of David Pearce's legacy and amounted to £107,305. Expenditure was £11,966.
The Groups total assets now stood at £136,378.
- 14. AOB**
AL will produce a Newslink item with information about the new AGM arrangements and send it to IB so that a Newslink can be published in May.
- 15. Next Meeting**
We would aim to hold another meeting late in May for about 1 hour to discuss:
- AGM/ awards
 - Research

There being no further business, the meeting concluded at 16.45.