

# HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

3rd April 2022, Start time 18:30

## Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Mike Cain (MC), Emily Bell (EB).  
**Apologies:**
2. **Previous Minutes** Version 1 of the 7<sup>th</sup> December minutes had been circulated and were accepted as correct.
3. **Trustee recruitment update** – (Hello to Emily!).  
**AL** Welcomed Emily Bell to the meeting. He would be asking the Trustees to vote on co-opting her as a Trustee after the meeting.
4. **AGM Planning.** The 2022 AGM will be held as a face-to-face meeting at the Tally Ho Conference Centre, Birmingham on July 3<sup>rd</sup>.  
AL intends to have three presentations, the intention being to leave good time for discussions and conversations. Suggestions were: Citizens Advice; Lily Rice; Research Updates; A medical support theme e.g. Coloplast.  
DH was prepared to stand for a further one year term if no other candidate has been found. All other trustees are happy to continue in their roles for another year.
5. **HSP Annual Awards.** Two nominees were offered and accepted by Trustees:  
**Awareness Award** – Estelle Marshall  
**Fundraising Award** – Tom Bell (Viking Run)  
JM would place an order for the trophies.
6. **TOR for Website committee**  
JM had produced a draft TOR document which had been circulated on 7<sup>th</sup> March. These were agreed as the starting point for the Website Committee with DH as Chair.  
JM Said that Jenni had already seen the TOR's and was happy with them, including her place on the committee.
7. **Face to face Meetings.**  
It was agreed that we should now remove all restrictions on face-to-face meetings and report this at the AGM.
8. **Committee Updates**  
**Meetings.** It was agreed that where possible clashes of dates should be avoided, but sometimes was inevitable. Explanations were given as to why members got invited to several forthcoming meetings. Our “50 mile radius” rule has this effect in narrower parts of the country.  
**Membership.** MP reported we had 14 new applications in the last 16 weeks. Many of these were asking for connections with local members and also connections with other parents with children. MP will contact Ian Bennett to help identify possible contacts.  
**Fundraising.** AL stated that Rachel Mortimer-Holdsworth was now able to devote more time to the group and it was hoped that she would have a strategy document defined with two to three months.  
**Research.** We had a volunteer named Annie Scott who was now preparing “plain language” summaries for some recent research papers. It was hoped that, when published, these will make it easier for members to understand the research better.
9. **Manchester Call feedback**  
The initiative relates to possible collaborative involvement with a research group. The research group gets access to large tranches of funding but needs “subjects” to guide and support their work. Some of the work will involve setting up databases. So this sits as a possible funding avenue, but no decisions have yet been made.

## 10. Member Grants

It was agreed that where member grants were being considered before 12 months membership had been established that the group should make further checks to satisfy Trustees about the validity of applications. DH would action this for the current application by asking local members to meet the applicant.

## 11. Finances overview/summary

JM produced summary accounts which were close to what the year end position was likely to be:

### FORECAST BUDGET FOR 2022-23

#### INCOME

	Income 2021-2022	Projected Income 2022-3
Subs	£4,724.77	£4,900.00
Unrestricted Donations	£6,485.31	£6,000.00
Restricted Donations	£110.00	£500.00
General Fund Raising	£2,247.68	£10,000.00
Restricted Fund Raising	£14,514.51	£8,000.00
<b>TOTAL FUNDS</b>	<b>£28,082.27</b>	<b>£29,400.00</b>

#### EXPENDITURE

	Expenditure 2021 - 2022	Projected Expenditure 2022-2023
S07 & 8 Fundraising expenses	£60.00	£1,000.00
S10 Research Grants	£15,000.00	£30,000.00 See Note 1
S10 Grants available to Individuals	£10,004.94	£12,000.00 See Note 3
S10 Newsletter	£119.94	£1,000.00
S10 Calvert Trust	£282.50	£9,717.50 see note 4
S11 Regional Meetings & conferences incl AGM	£0.00	£6,000.00
S11 Admin incl Trustees meeting expenses	£1,107.32	£4,000.00 See Note 2
<b>TOTAL EXPENDITURE</b>	<b>£26,574.70</b>	<b>£63,717.50</b>

#### CASH POSITION

<b>Money in bank 7/2/22</b>	<b>£129,645.91</b>	
forecast deficit		£34,317.50
Balance estimated at 30/4/23		£95,328.41

#### LIABILITY

Outstanding Grants approved but will still be outstanding on April 30th 2023		
Exeter £15k and Sheffield £45k		£60,000.00

#### NOTES

- 12 payments made to Exeter. 2 more of £15k each outstanding  
Grant of £60K (4x15K) was approved by the trustees to Sheffield in 2019 to be paid in 4 instalments, but no invoices as yet received.
- 2 Admin includes:
  - Membership of EURO HSP and Genetic Alliance
  - TS Host costs for website. Zoom costs
  - Expenses for committee meetings; booklets, posters and stationery costs and Euro confe
  - £600 deposit paid for Tally Ho 2022 AGM. David Pierces bequest will pay for lunches at the next live AGM as requested by the trustees.
  - Grants to Individuals up to £1000 confirmed Trustee meeting 8/5/21. 14 grants given in 2021-2
  - Calvert Trust has a fund of £10000 allocated from David Pierces bequest. The balance
- 3 will be carried forward each year until it has been used up.
- We are still waiting to receive a bequest from ? whose estate is being wound up and
- 4 being divided up amongst a number of charities .

## 12. Research Newsletter

AL believes a new issue is now due so will prepare one over the next two to three months.

There being no further business, the meeting concluded at 20.26.