

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

18th May 2023, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), John Mason (JM), Dave Harris (DH) Shanake Amarasinge (SA), Juan Vazquez Ruiz (JV), Mike Cain (MC) (part).

Apologies: , Mitesh Patel (MP), Emily Bell (EB).

1. AGM

It was agreed that the meeting will be held virtually with voting in advance, as per previous years. It will also be recorded and uploaded to YouTube. Planned date: Saturday 15th July – in the morning.

After discussion Adam agreed to contact the following groups:

- The Rome team we gave the research grant to in 2020
- Jovana and Sidney to see how are doing with their studies.
- The Plymouth or London research teams
- The Sheffield and Exeter teams
- Paul Gilbert talking about shame and compassion
(<https://www.psychologytoday.com/gb/blog/finding-a-new-home/201902/shame-and-compassion-qa-with-paul-gilbert>)
- “Student Voice” publication.

2. Trustee Elections. –

Trustee elections this year:

- Adam Lawrence – due to end of three year term
- Mitesh Patel – due to end of three year term
- Shanake Amarasinghe – first election
- Juan Ruiz – first election

Emily, Mike and Dave were elected last year or the year before and are not up for re-election this year. John is standing down as treasurer at the AGM, and indicated that he wished to stand down as Trustee. Mike Cain and Dave Harris said they were prepared to continue as trustees.

Adam reported: “I’ve been carrying on talking with people coming through the Reach volunteering website. In recent months I spoke with Carmen, who decided it wasn’t for her, and with Anand, who might come back to us. Carmini has also recently expressed an interest, but I’ve not had a conversation with her yet. There has been zero interest in this through any of our other channels.”

3. John’s other roles

John has handed on the Treasurer tasks to Shanake, but was prepared to continue with the of maintenance and operation of the membership database.

4. Secretary role.

DH said that he wished to stand down last year, but at the same time doesn’t want to leave the group in the lurch. AL asked various trustees if they would consider the role.. A discussion ensued. This was concluded as MC withdrew from the meeting.

5. Awards.

There have been a few nominations made for the awards so far:

Awareness	Fundraising
Lucy Begg – played character on TV – Waterloo Road	Estelle Hetherington – ran London marathon
Ian Bennett – organised potato pants over many years	Ian Bennett – organised potato pants over many years

Ece & Bridget – childhood HSP survey/work	
Jason Main – three peaks challenge	
(Tom Bell – nomination for charity of year at work*)	
(Peter Bateman – various fundraising over the years*)	

*Has previously won an award

It was agreed that Estelle Hetherington (Fundraising) and Ian Bennett (Awareness) should be this years recipients
AL stated the need to discuss how we process these in the future, as John has done this each time so far.

6. Finances & Budget

Financial report circulated, in essence the group had £125K in the bank. There were outstanding commitments which see this being reduced to £91K eventually.

AL discussed the Joy Rainey bequest - “currently (Nov 22) held up in the Australian courts. I looked back at my e-mails from 2021, in which I said that her estate was about £700,000, and would be divided equally between about 25 charities. I estimated that to be some £25k-£30k to us. That was a finger in the air estimate with no appreciation or understanding of taxes or other costs. I have had no further information since Nov 22 about the valuation or the timescale.”

Research Grant at Sheffield. Despite repeated efforts since the award of the grant, Sheffield have been unable to supply us with an official pro-forma invoice to request the funds, and they are still in our accounts.

JM made the point that if the research team at Sheffield had started their research without our funds, then it is difficult for us to see how they can use the funds in the way that they sought in their application.

Without action these funds have little prospect of them being used in line with their application. We need to ensure that our funds are used for the purposes that were agreed. A discussion took place about how to take this forward, with a suggestion made that if Sheffield were unable to (a) request their funds in an agreed way and (b) able to demonstrate that they would be used in line with their application, then we could consider withdrawing our funding, and free up those funds for other uses.

AL agreed to contact Channa at Sheffield to draw these points to his attention, and try and find an agreeable way forwards.

7. Future Trustee meetings

AL suggested that we plan to hold them every 2 months during the year, but avoiding one near the AGM, making 5 in total each year. This was agreed.

8. Trustee Responsibilities

Mike reminds us of the Charity Commission expectations for trustees -

<https://www.gov.uk/guidance/charity-trustee-whats-involved>

We also agreed that we would all complete DBS checks, and we need to make sure that plan moves forwards so that we actually do this. JV would provide a “DIY” guide.

9. Committee update - meetings.

Hilary and Jane have updated the meetings guide. JM commented that the guide was substantial. He wondered if it may put off people from holding smaller type meetings.

AL stated we still don't have anyone coming forward offering to be chair of this committee.

10. Committee update - research

AL stated we have one application in for a research grant from Cambridge. We would need to hold a committee meeting to discuss if we want to recommend this for trustee decision.

JV felt there was mileage in making a list of projects we could fund. After some discussion, it was agreed that AL will approach the research institutions and ask them for suggestions of projects they might be able to offer based on some "round number" budget suggestion (e.g. £500K). If there was felt to be some worthwhile suggestions it might be appropriate then to engage someone temporarily to draft appropriate funding applications. It was felt that unless a concrete project/aim was defined, it will not be easy to seek such funding.

11. Committee update - membership

No discussion or information, would await info from MP

12. Committee update - website.

- **Jenni status** – Continues full time working from home. HSP web tasks done when requested – usually within a few days.
- **Items changed:** Donations main page: minor amendments and updates. MC has suggested a single Donations button. Under consideration.
- **Contact forms**, 28 since last meeting;
- **Grant Applications**, From 6 individuals since last meeting
- **Work in discussion:** Mike has suggested an "Awareness" page to do with NHS/Social Services national reorganisation. Under discussion.
- **Management** Renewal of Business Web site, Domain and Security Certificate all completed OK in last two months.
- **Next meeting.** None scheduled at the moment.

13. Other items

MC has asked about using our resources to publicise HSP. AL was not sure if this comes under a specific committee or is a more general thing. "We should discuss - In principle I'm happy for us to consider using our resources to increase awareness of HSP. If anyone has ideas for things we can do, lets hear them – and then all we need is to find people who have the time to be able to action them."

Juan asks about expanding our membership database to include more details on peoples HSP types, and about contact/data sharing consent. AL "We should discuss – We'd need to balance the time taken to do this against any expected benefits from doing so. For that balance we'd need to more clearly understand the specifics of the database change and the new use of the data. There will be a GDPR overlay on top of all of this." After further discussion, we concluded that there was little value in expanding our database at this time as our membership numbers were small and the number of members who knew there relevant information was a smaller fraction of that.

Adam was also tasked with contacting research groups to ask if they see value in our extending our database with members gene diagnosis and/or making members accessible to them. The response would then determine changes to the database and a definition of a data collection project.

There being no further business, the meeting concluded at 20.32.