HSP Support Group
Minutes of the Trustees' Meeting held on Thursday 16th October 2025

Trustees Present:	Adam Lawrence (AL), Chairperson
	Mike Cain (MC)
	David Harris (DH)
	Estelle Marshall (EM)
	John Mason (JM)
	Mitesh Patel (MP), part of the meeting only
	Michael Payne (MPay), Minute Taker
In attendance:	Siang Ing Lee (Ing), part of the meeting only
Apologies from:	Phil Bungay
	Helen Payne

The meeting commenced at 7:30pm, no agenda had been agreed in advance, but the following points were raised by the trustees present.

1) World HSP/PLS day (AL).
AL reported that the following day, 17th October, would be World HSP/PLS day which had been instigated by the Spanish HSP Group. The objective was to raise awareness, recognition and possibly raise funding and he had put various things on the social media channels to promote the day. EM had a video (made from work with students at her local university) and it was agreed this would be added to the YouTube channel, with a link from the website (**action: AL/EM**).

2) Honorary members (JM).
JM raised the issue of the list of honorary members (mainly hospital consultants) which he felt was now out of date. It's important to have an up-to-date list for sending out newsletters etc. After discussion it was agreed the best way was to ask the membership who their current consultants/NHS contacts were and from their feedback update the list, JM would prepare a form to send to members (**action JM**).

3) Research grants (AL)
AL reported that he had received a call from Dr Channa Hewamadduma of Sheffield University about the research grant made to them. For the information of the new trustees, he explained that the research was into HSP7, but unfortunately several people had dropped out of the project, so it had not advanced; he understood approximately £4k of the £30k grant had been spent, but the remaining money was still available. Good due diligence had been made before the money was advanced, so we knew exactly what the project set out to achieve. AL was due to have another call with Sheffield University regarding the project going forward and would report back to the trustees. JM advanced the view that perhaps the remaining money should be repaid, and Sheffield University could then re-apply for a grant.

4) Discussion on current level of cash holding (MPay).
MPay prompted the discussion on the level of funding held and how best to spend the money to support our members. AL believed there were four options:

- Carry on as we are now – there are forms on the website for anybody wanting to receive a grant to carry out research work into HSP. This process happens twice a year.
- Be more pro-active by going out to known research teams to offer them grants; this was the approach JM preferred. (It was believed that Exeter, Sheffield & Cambridge were currently carrying out research into HSP).
- Work with other HSP Support Groups from overseas such as USA, Australia & Europe – there was concern from some of the trustees about taking this approach.

- At the 2025 AGM workshops had been undertaken to see what the members wanted from the Group.

It was agreed that any grants made would be towards research and not cures and we had to be very careful of scams. A discussion took place regarding increasing the level of grants to members, but it was noted that the level had been increased over the last few years and now stood at £1k and should remain at that level for the time being.
It was agreed we should progress the feedback from the AGM, Ing agreed to do this review but would not be able to do it until January (**action Ing**).

5) 2026 AGM (MPay).
The 2026 AGM was discussed, and AL recommended the same venue as 2025, Sense Birmingham, which was agreed. JM stated that the meeting should be as soon after the end of the year as possible and either 21/22 or 27/28 June 2026 seemed appropriate, AL agreed to check availability and if possible, book the venue (**action AL**).

6) Book (MPay).
EM advised that there were now two books being written and she and Pip had cross contributed on the books. It was hoped the books would be completed by Christmas and they would be self-published. All revenue would flow to the Group, but the main objective of the books was to provide a resource to our members and people with HSP, which might increase our membership.

7) Finances (MPay).
MPay had circulated the accounts as of 30 September. MPay &DH confirmed to MC that a tip did not have to be given when a donation is made via Just Giving. MPay confirmed that he still didn’t have access to the Barclays bank accounts. JM believed that Barclays had all of the information needed but was waiting to hear from Barclays that MC’s passport was acceptable. AL agreed to contact Barclays to try to speed up the process (**action AL**).

8) Committees (AL)
AL believed that the concept of Committees was good but was concerned that they were not active enough or were not working efficiently. There then followed a discussion on the Committees.
DH felt that the Website Committee was working well at the moment, but was concerned that in the medium/long term two new people with IT expertise would be needed when JM and himself became less involved.
There was concern regarding the functioning of the Research Committee, and perhaps, because of AL’s many other responsibilities, another Chairman might help.
AL suggested that the “How can you help the Group” part of the website might be updated

9) National Disease Registration Service, NDRS (MP & Ing)
Ing recommended that the Group share member data with the NDRS, but before that could happen the following would need to occur:

- The privacy notice on the website would need updating.
- The consent of all members would be required.
- The new member Registration Form would need updating.
- Additional information would be required from members (i.e. date diagnosis).

It was conceptually agreed that we should share data but AL and Ing would liaise to ensure that all aspects were understood and acceptable (**action AL & Ing**). It was also thought that if we had to contact members on this issue then it was a good opportunity to cleanse the database.

10) Other matters.
The following points were also discussed during the meeting:

- AL confirmed that PB was a trustee and had been appointed at the AGM. *(later correction: PB was not appointed at the AGM but was invited to become a trustee in an e-amil from AL on 20 August 2025).*
- HP, as secretary, was responsible for updating the Charity Commission website. She would need assistance from DH to take over this responsibility (**action HP & DH**).

The meeting ended at 9:15pm.