

Minutes of the Meeting at 7.30 on 19th March 2026

Attended: Adam Lawrence, David Harris, Estelle Marshall, Mitesh Patel, Michael Payne, Helen Payne, Phil Bungay and Siang Ing Lee

Apologies from Mike Cain

1. **Matters arising from the previous minutes:**

None

2. **NDRS (National Disease Registration Service) Database**

It was decided that Mitesh would draft a change to the new membership form to include whether members would be happy to be added to NDRS. It was also discussed that we should ask who their neurologist was and where they are based. The plan is then to create a form for all members to complete at some point. **Mitesh**

3. **Chairman's Report**

a. **Database**

A meeting was held with John's son Nik, AL, MPay and Dan Kitchen to try and gain proper access to the database. Currently the people with access to the database are Adam, Mitesh and Michael. Emails have not been going out to the relevant area members about forthcoming meetings. Adam thinks he can get round this using postal area codes in members addresses. **AL**

b. **AGM 26th July**

Speakers were discussed. HP has approached Lily Rice and Ian Bennett.

Lily Rice may get through to a swimming competition so she will be away but was happy to speak. Ing suggested asking Lorenzo. **Ing**

Phil suggested he could ask the Uni of Birmingham sports science to do a piece on staying well with HSP **PB**

c. **Research information**

Adam has a meeting planned on 26th March with Channa at Sheffield about the research project and if it is happening. There is also continuing research possibility with the Molli suit proposal at Plymouth with MSC research students and Lisa.

4. **Treasurer's Report**

a. Michael had sent out the February accounts earlier in the week. They showed a YTD surplus of £7,000 and there was currently £162k in cash, mainly in the deposit account. No questions were raised on the accounts.

- b. The year end accounts are fast approaching, and he referred to an e-mail he had sent out on 14th March recommending that we change to the Receipts and Payments method of preparing the accounts. This was a more appropriate format for a small charity like ours, the trustees agreed with the recommendation.
- c. Michael asked that we formally approve the year-end accounts at the next trustee meeting in May. He has asked a friend, Mick Dunn, to be the examiner of the accounts. Mick is a retired chartered accountant who had worked for many years at Johnson Matthey in different finance roles and Michael believed he had the necessary experience to be the examiner. The trustees agreed to the appointment of Mr Dunn and requested Michael to organise the appointment.
- d. Re-registration for Gift Aid with HMRC has now been submitted. Most people had replied to Michael's request that we could still claim gift aid on their behalf, but 13 have not replied.
- e. There are still some problems with Barclays. Mitesh explained that he can still not access the Barclays account online. **Mitesh**

5. Policies Update

Some of the policies still need to be updated but these are PDF form. Adam said he would convert them to word documents. They are on the database again and cannot be accessed. Michael said he would review them once he has word versions from Adam **AL**

6. Information from Ing

- a. The UCL study by Lorenzo on research into genetic testing on HSP patients with no known HSP gene. He needs to create a study and wants to start this mid-March.
- b. The research by Rahema requires some dates in May or June for a meeting,
- c. The Newcastle University research project want children under 25 to research movement disorder. They have asked for a letter of support for this, and it was agreed that this should be given. **AL**
- d. The research questions that were created at last year's AGM, which Ing wrote up, were discussed. It was agreed that they should be put on the website for potential research students to use. It was agreed that these should be in one booklet. **Ing**
- e. It was discussed whether we should have a stall at the ABN Conference from 6-8th May in Birmingham, where researchers and medical staff would be attending. Michael raised the cost and was concerned that the stall could be manned for all 3 days. Both EM and PB agreed they would be happy to man the stall. Ing and Mitesh outlined the huge potential benefits of doing this in terms of research possibilities. It was agreed Mitesh should try to book the stall. **Mitesh
EM PB**

7. Any Other Business

- a. HP reported that there had been 9 emails from members in the last three months and 2 grants awarded. Dan Kitchen has signed and returned the confidentiality report.
- b. HP mentioned that her daughter in law, Saaga, has experience in marketing and web site work and would be happy to assist the charity in these areas. It was agreed that she would help in these areas and Adam said he would send some marketing suggestions.
- c. Adam reported that the meetings committee wondered if they should try to increase membership. There are many people in UK with HSP that are not aware of the HSP support group. The challenge is to get clinicians to recommend the charity to HSP patients.
- d. Pip's book will hopefully come out in the summer now. Estelle's book is out and looks good. It is available on Amazon to purchase.
- e. The Euro HSP group will celebrate World HSP day on October 17th in Amsterdam.
- f. A grant request from the University of Plymouth had been received to study the benefits of Mollii suits. The request would be reviewed by the Research Committee.
- g. Adam reported he would be having a call with the University of Sheffield to discuss the grant we had given to them two years ago. **AL**

The meeting ended at 9:10pm.