

Minutes of the Meeting at 7.30 on 27th November 2025

Attended: Adam Lawrence, Mike Cain, Estelle Marshall, Mitesh Patel, Michael Payne, David Harris and Helen Payne

1. Matters arising from the previous minutes:

- a. Adam has still not spoken to Channa about the Sheffield research, **AL**.
- b. AGM date now agreed as 26th July. Adam is to let the organisers know so it can be booked and need to be put on the website and an email sent out to membership, **AL**.
- c. Michael P still has no access to the account. Some trustees have been taken off to facilitate this. Adam said he will ring Barclays to try and sort this out, **AL**.
- d. The 2024/25 accounts and report still need to go onto the Charity Commission site. Dave said he would email the documents to Helen so that she could try and put it on. **DH and HP**.

2. Chairman's Report

- a. Lisa Bunn of Plymouth University was going to request a grant of £30,000 over two years to research the benefits of Mollii suits. Estelle reported that she would have a paid research role in this project so has a vested interest, consequently she would withdraw from any discussion and decision on this matter. The application was due to be submitted by 19th December, which Mike noted was after our semi-annual deadline of 30th November. As there were currently no other grant applications it was decided to extend the deadline for this application until 31st December.

3. Mike Cain Questions

- a. World HSP Day. He said that few people from UK joined in and it was dominated by the USA's organisation. It was discussed how we should promote next year. But it was agreed that the social media campaign did raise awareness.
- b. He asked about the Euro HSP projects. There is one for SPG4 and another for SPG11 and 15.
- c. There is an international Drug repurposing conference in May 2026 in Brussels. It was felt it would be beneficial to have a representation at the conference.
- d. He asked what we planned to do with the money we have. Adam explained that the money would go to fund projects, pays grants to members and pays for research projects.

Ing Patel, will feed back the list of ideas for research from the members at the AGM, **IP**.

It was suggested that we should have a fund for helping Paralympians that have HSP or research students. It should be put on our social media and on the website, where people can request funding.

4. Estelle Feedback

- a. Estelle and Phil went to the Rare Disease Showcase. Estelle said there is a new app being created called ADVOCA which is only on Apple at the moment, but it will have appointments on and will link to relevant leaflets and information which will inform patients.
- b. Rare Diseases Day is 28th February 2026. The plan is to launch Pip's and Estelle's books at that time. EM to send updated book to Adam and Helen to check for errors, **EM, AL and HP**.
- c. She has contacted all physiotherapist at universities to send a video about HSP and now plans to do the same for occupational therapists.

5. Treasurer's Report

- a. Michael sent out the October accounts earlier in the week and welcomed any questions, there were none.
- b. He has now chased non-paying members twice and feels that is enough.
- c. He is trying to sort out claiming Gift Aid. He has had to contact HMRC regarding access to their site and been told that we should have re-registered with HMRC in 2019 when we changed to a CIO. It was agreed that Michael along with Adam & Mitesh would be the trustees registered with HMRC for Gift Aid

6. Membership secretary

Mitesh reported there had been 10 new members since the last meeting.

7. Any other Business

- a. Pip has sent out two newsletters so far and is in the process of doing the third. She is unwell now so there may be some delay.
- b. There was little feedback from the various committees. Adam thinks we need to find someone else to run the research committee.

