

AGM Minutes

26th July 2026 at Sense Touchbase Pears, Birmingham

Apologies were received from:

David and Carolyn Harris, Mike Cain, Phil Bungay,

Chair's Report

Adam reported that voting had taken place for election of three trustees. The votes were shown for Phil Bungay, Adam Lawrence and Mitesh Patel and they were all duly elected. About 12% of the members voted.

Adam told us that Estelle would be becoming Chair in the coming year, but that he would be staying on as a trustee. He pointed out that in his time he has seen us change to become more digital including adding YouTube channel and the meetings have been online. He told us that Estelle has already made a huge contribution by setting up the counselling with Rare Minds, writing a book and attended many events on our behalf. Adam thanked the trustees for their efforts.

He said there are 8 trustees so room for two more if anyone is interested.

The various committees were discussed:

- a. The **Meetings Committee**: there are currently face to face meetings and two zoom meetings a month. There has been one organised in Scotland and one in Northern Ireland. There is a new group in Hitchin. There continue to be monthly online zoom meetings held by Ian Bennett and Estelle Marshall.
- b. **Newsletter**: Pip Lee has now produced 4 newsletters which are online and 30 members receive these through the post.
- c. **Research Committee**
 - New research is planned into Mollii suits with Plymouth University. A feasibility study is being carried out and 20 people with HSP will test them to ascertain if they are beneficial.
 - We are contributing to the Euro HSP project and Dr Guilia Guarato has won the Adolf -Struempell award for her research into the Italian part of this.
 - There are now some potential research topics on our webpage for researchers to hopefully wish to do.
- d. **Website Committee** –Thanks were given to Jenni Preston for continuing to update the website. We have a currently have a problem accessing the database, so a new database package needs to be sorted.

Membership Report

Mitesh reported that there are about 40 to 50 new members per year. This year there have been 21 new members. There has been a key issue with accessing the database.

Fundraising

Adam thanked people for their fundraising efforts particularly thanking Emy Sims and her family for climbing Ben Nevis and to Trevor Smart for doing the Half Iron man.

The British Karata club (KUGB) have designated our charity for this year up to May 2027. Estelle attended their launch which was at Karate on the Beach in Blyth.

New HSP Books

Pip Lee's Book: "A Guide to living with HSP" has just come out and can be bought on Amazon. All proceeds go to our charity.

Also Estelle Marshall's book: 'Living well with HSP' can also be bought on Amazon

Counselling opportunities

We are working with Rare Minds to provide counselling. David Phipps will be our counsellor, members can contact him and HSP support group will pay for a series of sessions. This service will be formally launched to our members at the end of the summer.

UCL Open Day

There is going to be an HSP open day at UCL in early 2027. There will be presentations from clinicians and scientists with opportunities to ask questions. It will be in Queens Square in London.

World HSP Day

This will be on Saturday 17th October and last year there were many social media posts with people making the gene symbol.

Social Media

There have been 20,000 views of videos on social media and all of our AGMs have been viewed 1,700 times. Members were reminded that there are links on YouTube, X, Facebook and LinkedIn.

Secretary Report

Helen reported that there have been 5 trustee meetings since the last AGM, there have been 14 grants and one for the Calvert Trust. There have been 60 enquiries on the website. Helen thanked Jenni Preston for maintaining the website.

Treasurers Report

Michael presented the annual accounts to 30 April 2026. He reported that income for the year was only £24k compared to £61k in the previous year but this was mainly explained by a legacy of £30k in the previous year from the Jo Rainey estate, also fund raising was lower last year, but as we have heard is going very well this year.

Expenses were slightly lower in the current year, primarily because a grant of £11k had been made to Euro HSP in the previous year that was not repeated in the current year. This meant that income exceeded expenses by £5k and total cash funds now stood at £160k, of which £2k was in a current account and £158k in a deposit account, both at Barclays.

Michael advised that the financial statements had been signed off by the Examiner, Mick Dunne, to whom he offered his thanks.

Any other business

Des Williams thanked Adam and the trustees for all their hard work.

Date of next AGM/ Conference: Touch Sense base Pears in Birmingham on Sunday 25th July 2027

In the afternoon awards were awarded to Emy Sim and Trevor Smart (who was not there) for fundraising and awards were given to Penny Cohen, June Masding, Jane Bennett and Hilary Croydon for raising awareness about HSP.

We then had four speakers through the afternoon on staying active with HSP, taking part in the Flying scheme for the disabled, and an update on genetic research being carried out.