

## AGM Minutes

27<sup>th</sup> July 2025 at Sense Touchbase Pears

### **Apologies were received from:**

John and Sonia Mason, David and Carolyn Harris, Mike Cain, Pip Lee, Juan Vazquez Ruiz, Hilary Croydon, Petula Baker, Glenys Browne, Nigel Bulbeck, Joan Carter, Betty Cawley, Angela Cooke, Stephanie Flower, Jane Hardle, Anne Taylor, Tess Trafford and Lisa Wyan

### **Chairmans Report**

Adam thanked June and Penny for organising the venue for our AGM.

The votes were shown for Estelle Marshall, Michael Payne, Helen Payne, David Harris and John Mason and they were all duly elected. About 18% of the members voted. The current trustees are Adam, Mitesh, Mike Cain and the forementioned.

The various committees were discussed:

- a. The meetings committee - there are currently face to face meetings in Birmingham, Feering and Milford. Meetings have started in Stoke on Trent, Staffordshire and Leeds. There are hopes of starting up meetings in Glasgow and Milton Keynes. There continue to be monthly online zoom meetings held by Ian Bennett and Estelle Marshall.

Pip Lee was thanked for taking on the Newsletter and having produced the first one and is hoping to produce the second one in September.

- b. Research Committee -we are contributing to the Euro HSP SPG 4 project. We had a student (Arush), who has written a piece on HSP for his 2024 student voice award.
- c. Website Committee – no major changes but thanks were given to Jenny Preston.

### **Membership Report**

Mitesh reported that there are 361 members which is 48 more than 2024. There are 135 honorary members.

### **Fundraising**

Adam thanked people for their fundraising efforts particularly thanking Mark McCall, Jacob Day and Helen Payne for their variety of raised funds.

HSP Book – Pip is hoping to complete this by the end of October.

Social media gets 18,0000 views on our videos on YouTube, Facebook, Instagram, X and LinkedIn.

HSP can be added to the National Diseases Registration Service. HSP group plans to ask the membership if they would like to be added so that researchers can identify numbers with HSP.

### **Secretary Report**

Helen Payne gave the report on behalf of Dave Harris. There have been 58 enquiries on the website and 10 grants awarded. Helen thanked Dave for all his hard work over the years.

## **Treasurers Report**

Income was from: Donations £41,997 (£30,000 from the Joy Raynes estate) giving £30,000. Charitable activities raised £12,812 and subs were £5,700.

Expenditure was Just Giving cost £403, Grants £6,421, Research £10,760 and newsletter £3,420

Total reserves of the Group are £155,106.

Thanks were given to John and Sonya Mason for their work as Treasurer for the last 20 years and to Chris Harvey who audited the accounts.

Date of next AGM to be agreed by the committee.