

## Trustees' Report, Year Ending 30<sup>th</sup> April 2026

### Structure Governance and Management

The charity, also known as the HSP Support Group, is governed and administered by a committee of 8 volunteer trustees. The trustees consider that all actions taken during the year were in accordance with the constitution, dated 4 January 2019. The trustees meet several times a year or correspond by email to discuss the activities of the group and its position, make decisions on activities and expenditure. Five meetings were held during the year by Zoom and the trustees met in person at the 2025 AGM in July 2025.

Unfortunately, in November 2025 John Mason passed away, John had been a trustee for many years as well as Treasurer for a number of those years and will be sadly missed. Also, during the year Juan Vazquez Ruiz resigned as a trustee and was replaced by Phil Bungay. At the 2025 AGM Helen Payne took over as Group Secretary and Michael Payne became Treasurer. At the 2026 AGM Phil Bungay, Mitesh Patel and Adam Lawrence will offer themselves for election or re-election as trustees for a three-year period.

### Objectives and Activities

The group's mission statement is: **People with Hereditary Spastic Paraplegia (HSP), their families and carers are at the heart of everything we do.**

- *Our information and support helps improve the quality of life for those affected by HSP.*
- *Our friendly support community helps with sharing ideas and reducing feelings of isolation.*
- *We support research into HSP, including developing treatments and improving understanding.*

The mission statement articulates how the Group fulfils its charitable objects which are concerned with promoting and protecting physical and mental health and advancing education.

The Group provides a friendly supportive community with various ways for members to keep up-to-date and communicate with each other:

- An Annual General Meeting reports the activities of the group.
- Presentations after the AGM from HSP specialists and relevant individuals help people explore topics relevant to HSP.
- Regional meetings are regularly held around the country and on-line aiming to encourage conversation and reduce feelings of isolation
- A Newsletter is published 2-3 times a year
- A website and social media channels provide recordings of online events, relevant information and allow discussions on appropriate topics
- The group is involved with relevant umbrella organisations to help promote HSP

The Group provides various ways to support members and to promote research into HSP:

- Supportive community grants are available to members to help with the purchase of mobility aids or other equipment
- Grants are available to support activities and projects researching aspects of HSP

### Achievements and Performance

The group has worked on its public benefits with the purposes of reducing isolation and keeping people informed and involved:

- The 2025 AGM was held at Sense Midlands in Birmingham, the first face-to-face meeting held following Covid.
- Following the formalities of the AGM there were several presentations: An exercise class led by Estelle Marshall, a presentation from the University of Plymouth on Mollie suits, and group discussions were held with attendees to identify potential areas for research.
- Around 20 meetings were held during the year, a combination of Zoom and face to face.

- The Group had a stall at the Manchester Rare Conditions Event in Manchester in November 2025 and will have a stall at the Association of British Neurologists Annual Meeting held at the ICC in Birmingham in early May 2026.
- Pip Lee became editor of the newsletter during 2025 and there have been three issues published since the 2025 AGM.
- The Group is funding a book about HSP being written by Pip Lee, which is expected to be published in summer 2026.
- Estelle Marshall has also published a book called Living Well with HSP, a journalling self-help book available on Amazon.
- Social media groups for those with HSP and their carers were supported.

Money is raised from subscriptions and fund-raising activities undertaken by members and friends. Ten members successfully applied for member grants, generally with the aim of purchasing mobility aids. In total £9,749 was approved for them. In addition, one member successfully applied for funding towards a holiday with Calvert Trust (£830).

### Membership

The general level and pattern of membership is similar to previous years. Whilst many people are members for the longer term, there are always new members joining and other members leaving. The level of membership continues at just under 400. We continue to track reasons for leaving to ensure we're responding to member needs as much as possible within our resources.

### Research

In March 2026 the trustees received an application from Plymouth University for funding towards a project to Independently Evaluate the use of the Exopulse Mollii Electrostimulation suit for people with HSP, developing their initial work presented at our 2025 AGM. At the trustee meeting held on 14 May 2026 the trustees approved the grant application.

The group is also in discussion with Sheffield University about re-starting their research work into SPG7 which was approved by the group in 2020, part funded in 2023, but which is substantially incomplete.

### Financial Review

- Income: £24,321 (last year £ 61,045)
- Expenditure: £18,970 (last year £ 23,490)

There was a surplus of £5,351 for the year (last year a surplus of £ 37,555). The reduction of surplus this year was because last year an interim donation of £30,000 was received from the estate of Joy Rainey.

At the end of the financial year (30 April 2026) the Group has net assets of £160,457 (last year £155,106) held entirely in its bank accounts. These assets were held in reserve to meet member benefits, research funding, running costs and contingencies in future years.

As noted under Research, the application from Plymouth would result in the charity making a grant of £15,000 in the 2026/27 financial year and a further grant of £14,627 in the financial year 2027/28.

Monies raised for research are assigned to a restricted account which will then be used for research grants in future years. At the end of the year £8,737 is held in a restricted account (last year £5,481).

The Trustees consider that the Group is financially sound. The Trustees consider a reserve of around £25,000 should be held, which would cover running costs and grants to members in a normal year (but excluding any research grant). There are significant funds beyond this figure. The Group has not given any guarantees nor is any debt outstanding at 30 April 2026.

The financial statements have been prepared under the Receipts and Payments Basis in accordance with the Charity Commissioners guidelines and with regard to guidelines on public benefit.

Adam Lawrence  
Chair

Date: June 2026