



Charity name: Hereditary Spastic Paraplegia Support Group  
Charity no: 1181539  
18 Lodmoor Avenue, Weymouth DT3 5AF

Trustees: Shanake Amarasinghe, Emily Bell, Mike Cain,  
Dave Harris, Adam Lawrence, John Mason,  
Mitesh Patel, Juan Vasquez Ruiz

## Trustees' Report, Year ending 30<sup>th</sup> April 2023

### Structure and Management

The charity 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. 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. All meetings during the year were by Zoom.

Two members were invited to attend trustee meetings and were co-opted as trustees: Shanake Amarasinghe in November 2022 and Juan Vasquez Ruiz in January 2023. They will stand for election at the AGM in July.

### Activities and Objectives

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 featuring presentations from HSP specialists and other relevant individuals
- Regional meetings are regularly held around the country aiming to reduce the isolation of members
- A Newsletter is published 2-3 times a year
- A website and social media channels provide information and allow discussions on relevant topics

The Group provides various ways to support members and promote understanding of and 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 projects researching aspects of HSP
- The group is involved with relevant umbrella organisations to help promote HSP

### Achievements and Performance

Although activities this year have again been constrained by the restrictions imposed as a result of coronavirus, the group has worked on its public benefits with the purposes of reducing isolation and keeping people informed and involved:

- The 2022 AGM was held virtually, via the Zoom platform
- The presentations usually made at the AGM were also held virtually over summer of 2022
- Recordings of the AGM and the presentations were posted to a YouTube channel for the group so that members or the public can view them at any time
- Meetings during the year were held via Zoom and face to face:
  - 12 national meetings (Zoom)
  - 10 regional meetings (face to face)
  - 2 focussed meetings (families. SPG11, SPG15) by Zoom
- 2 editions of the newsletter were produced (May 22, Oct 22)
- Social media groups for those with HSP and their carers were supported
- 2 awards were made at the 2022 AGM recognising contributions made by individuals to help raise the profile of HSP and for fundraising.
- The group agreed to continue annual contributions to an international prize for research into treatments and therapy for those with HSP
- Trustees have attended a number of relevant meetings and have reported their observations to members

Home nation meetings (WAL and SCO) have lapsed with a shortage of volunteers able to host them.

Money is raised from subscriptions and fund-raising activities undertaken by members and friends. Fund raising has not recovered to pre-pandemic levels.

No new research applications were received this year. Two research grants are still active, one in Exeter and one in Sheffield.

Nine (9) members applied for member grants, with the aim of purchasing mobility aids. In total £6,409 was approved for them.

## Financial Review

Income: £ 19,427.45 (last year £ 32,742.21)  
Expenditure: £ 26,468.00 (last year £ 29,591.97)

There was a deficit of £7,040.55 for the year (last year a surplus of £ 3,150.24).

At the end of the financial year (30/4/2023) the Group has net assets of £125,325.43 held entirely in its bank accounts. These assets were held in reserve to meet benefits, research funding and contingencies in future years.

All monies raised for research (£4,107.51 with collection costs of £113.68) were assigned to a restricted account. The account was used as part payment for research grants which totalled £15,000.

The Group has offered to fund research at Exeter and Sheffield Universities with offers to support research at a rate between £10,000 and £15,000 per year (depending on the availability of funds) for the 4 years of a PhD studentship at each university. Three (3) payments totalling £45,000 have been made to date to Exeter. We are still waiting for a formal proposal from Sheffield before making payments.

There are no other outstanding liabilities. Fundraising comes mainly from outdoor events which have not recovered to levels before the coronavirus epidemic. However there are sufficient funds to enable the Group to operate.

The Trustees consider that the Group is financially sound.

The Trustees consider a reserve of around £15,000 should be held to meet contingencies and that there are significant funds beyond that figure.

The accounts have been prepared in accordance with the Charity Commissioners guidelines and with regard to the guidelines on public benefit.

John Mason  
Treasurer

Adam Lawrence  
Chair

Date: 30 May 2023