

## Trustees' Report, Year Ending 30<sup>th</sup> April 2024

### Structure and Management

The charity is governed and administered by a committee of 6 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.

During the year one trustee stood down and there has been no interest from other people wishing to become trustees. At the AGM in 2023 Shanake Amarasinghe was appointed as treasurer for the group.

### 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 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 2023 AGM was held virtually, via the Zoom platform
- Presentations following the AGM were held virtually over summer of 2023
- Recordings of the AGM and most presentations were posted to our YouTube channel so that members or the public can view them at any time
- Around 20 meetings were held during the year, a combination of Zoom and face to face
- 1 edition of the newsletter was produced (August 23)
- Social media groups for those with HSP and their carers were supported

- 2 awards were made at the 2023 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

Money is raised from subscriptions and fund-raising activities undertaken by members and friends. Eight (8) members applied for member grants, with the aim of purchasing mobility aids. In total £4,709 was approved for them. No members applied for funding towards Calvert Trust holidays.

## Membership

The general level and pattern of membership is similar to previous years. Whilst many people are members for the longer term, new members join throughout the year and other members leave. We continue to track reasons for leaving to ensure we're responding to member needs as much as possible within our resources.

## Research

The group has agreed to provide funding towards the first two years of a project run by EuroHSP into treatment options for SPG4. One research application was received this year from Cambridge for a project researching SPG7, this was agreed but payments have not yet been made. One of our members has applied for funding towards their tuition fees studying HSP.

The Group is currently funding research at Exeter and Sheffield Universities 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. This year, the first two payments of £15,000 have been made to Sheffield.

## Financial Review

Over the year 1/5/23 to 30/4/24 the groups accounts show:

- Income: £ 31,595 (last year £ 19,427)
- Expenditure: £ 39,370 (last year £ 26,468)

There was a deficit of £ 7,775 for the year (last year a deficit of £7,040).

At the end of the financial year (30/4/2024) the Group has net assets of £117,551 held entirely in its bank accounts. These assets were held in reserve to meet benefits, research funding and contingencies in future years. There are no other outstanding liabilities.

This year saw an increase of income on last year from fundraising from members and their friends and family. 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 there are significant funds beyond this figure.

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

Adam Lawrence  
Chair

Shanake Amarasinghe  
Treasurer

Date: 29 July 2024