



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

Trustees: Ian Bennett, Mike Cain, Neil Cuthbertson  
Dave Harris, Adam Lawrence, John Mason,  
Mitesh Patel,

## Trustee's Report, Year ending 30<sup>th</sup> April 2021

### Structure and Management

The charity is governed and administered by a committee of 7 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 digital meetings.

One member was invited to attend trustee meetings and was appointed as a trustee in September 2020.

### 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:

- In addition to the 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 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 2020 AGM was held virtually, via the Zoom platform
- The presentations usually made at the AGM were also held virtually
- Recordings of the AGM and the presentations have formed a new YouTube channel for the group so that members can view them at any time
- The groups regional meetings during the year were held virtually, with 15 successful meetings held. The virtual meetings are especially helpful to those who are unable to travel to any of the usual meeting locations
- New regional virtual meetings were established in South Wales and Scotland
- 2 national virtual meetings were held
- The groups updated website was launched in June 2020
- 3 editions of the newsletter were produced (May 20, October 20, March 21)
- Social media groups for those with HSP and their carers were supported
- The first recipients of our two annual awards were made at the 2020 AGM recognising their important contributions to help raise the profile of HSP and for fundraising.
- The group agreed to contribute to a new 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. Fundraising during the year was limited due to the coronavirus pandemic, although several events and activities took place including sponsored events and a virtual potato pants music festival.

Three research grants were agreed this year including funding over 4 years towards two PhD students, one in Exeter and one in Sheffield.

Two (2) members applied for member grants, with the aim of purchasing mobility aids. In total £1,500 was approved for them.

During the year the group has worked on its governance:

- The committee structure is considered to be working well.
- Policies have been reviewed and updated as needed, with new policies prepared and agreed: code of conduct, register of interests, gifts, control of documents and control of minutes.

## Financial Review

Income: £ 14,244.85  
Expenditure: £ 21,989.52

There was a deficit of £7,744.67 for the year.

At the end of the financial year (30/4/2021) the Group has net assets of £129,215.74 comprising £128,615.74 held in its bank accounts and a prepayment of £600 made to book the venue for the 2022 AGM. These assets were held in reserve to meet benefits, research funding and contingencies in future years.

All monies raised for research (£959.29 with collection costs of £18.208) were assigned to a restricted account. The account was used as part payment for research grants which totalled £ 17,000.

The Group has committed funds to Exeter and Sheffield Universities with offers to support research at the rate of £10,000 per year for the 4 years of a PhD studentship at each university. This commitment has a proviso on there being funds available.

There are no other outstanding liabilities. Fundraising comes mainly from outdoor events which have been stopped in the last year by 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: 24 May 2021