



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

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

Trustee's Report

Structure and Management

The charity is governed and administered by a committee of 6 volunteer trustees, working within the Groups constitution agreed by members at the 2018 AGM, and available on our website. The trustees consider that all actions taken during the year in administering the CIO were in accordance with the constitution. The trustees meet several times a year either in person, by video conference or by email to discuss the activities of the group and its income and make decisions on expenditure.

One trustee resigned during the year and 2 members were invited to attend committee meetings with a view to their being proposed for election as Trustees, and one was appointed as a trustee in February 2020.

Recruitment of trustees and succession planning is being broadened outside the current membership to include personal networks such as LinkedIn.

Activities and Objectives

The groups 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 Group aims to fulfil its objectives by supporting members and assisting research. The Group provides various ways for members to keep up-to-date and communicate with each other:

- An Annual General Meeting features lectures from HSP specialists, and other relevant individuals
- Regional meetings are held around the country with the purpose of reducing the isolation of members
- A Newsletter is published to our members 2-3 times a year
- 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 the condition
- An e-mail discussion group system enables members to share information and experiences
- Social media including several closed HSP FaceBook groups managed by members of the Group to allow discussions on relevant topics with similarly affected people.

Achievements and Performance

Money is raised from subscriptions and fund-raising activities undertaken by members and friends. The Potato Pants music festival in Dorset is becoming established as a regular event, it produces an income for the group, and its audience is growing.

A past Chairman of the Support Group, David Pearce, made the Group a beneficiary in his will and we received £86,704.

No research grants were made this year although we have received 3 applications for funds. The applications were received too late to be processed in this financial year.

Four (4) members applied for support to purchase mobility aids and grants totalling £3,177 were approved for them.

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

- 16 regional meetings were held during the year
- 2 editions of the newsletter were produced
- Social media groups for HSP sufferers and their carers were supported
- Tests are planned to explore the viability of holding member meetings by on-line video conference
- Discussions were held with the Calvert Trust for the group to promote and subsidise outward bound activities for our members. This was an activity supported by David Pearce and a limit of £10K was put on the financial support out of his bequest to the group.
- Two annual awards are being established to recognise the important contributions made by members and to help raise the profile of the group. One is for fundraising and one is for raising awareness of HSP.
- Trustees have attended a number of relevant HSP and rare disease meetings and have reported their findings/observations to members, and trustees have taken the opportunity to contribute to discussions and talk to stakeholders at these events.
- Information on the risk of complications from coronavirus infection have been summarised from the British Association of Neurologists advice and given to members after discussion with UK HSP medical specialists.

During the year the group has also worked on its governance:

- It has confirmed a new committee structure for the group, agreeing Terms of Reference and appointing initial committee members and trustee representation. The committees now active are: Membership, Research, Fundraising and Meetings
- Two other committees have been identified: Newsletter and Website & Social Media. Terms are being developed for these committees.
- Progressed the group's new website. A prototype website has been delivered and approved.
- A new approach for considering research grant applications is being trialled to improve transparency on the decision making process.

Financial Review

Income: £ 107,269.86
Expenditure: £ 11,349.28

There was a surplus of £ 95,920.58 for the year.

At the end of the financial year (30/4/2020) the Group has net assets of £136,960.41 comprising £136,360.41 held in its bank accounts and a prepayment of £600 made to book the venue for the 2020 AGM. These assets were held in reserve to meet benefits, research funding and contingencies in future years.

All monies raised for research (£862.29 after collection costs of £23.81) were assigned to a restricted account. No payments from this account were made this year.

There are no outstanding liabilities. Fundraising comes mainly from outdoor events and these have been stopped in the last 3 months by the coronavirus epidemic. This shutdown is expected to continue into the next financial year 2020/21. 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
Chairman

Date: 28 May 2020