



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

Trustees: Ian Bennett, Della Brookman, Mike Caine,
Dave Harris, Adam Lawrence, John Mason

Trustee's Report

Structure and Management

The charity is governed and administered by a committee of 6 volunteers, working within the Groups constitution agreed by members at the 2018 AGM, and available on our website. The trustees consider that all actions they took during the year in administering the CIO were in accordance with the constitution. The committee meets several times a year to discuss the activities of the group, its income and make decisions on expenditure. Meetings are also held by email to conduct the ongoing business of the charity, including progressing applications for grants.

Recruitment of trustees is done by asking for volunteers at the AGM and through wider personal networks.

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
- A telephone and e-mail Help Line service offers advice and support to members
- Grants are available to members to help with the purchase of mobility aids
- 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.

Research was supported with a grant of £10,000 to Exeter University where a group is investigating nervous disorders. The payment is our third and final payment of £10,000; the total grant of £30,000 funded a research student for 3 years.

Eight (8) members applied for support and grants totalling £6,000 were approved for them.

16 regional meetings were held during the year and 2 editions of newsletter were produced, both with the purposes of reducing isolation and keeping people up to date. The group aims to establish a greater number of meetings.

During the year the group has also:

- Agreed a mission statement for the group
- Developed an improved process for considering research grants,
- Agreed to pay for room hire costs for the regular meetings around the country
- Developed a plan of action following member discussions at the 2018 AGM
- Contributed to the consultation on medicinal use of Cannabis
- Provided the patient voice to a research project establishing a physical activity programme
- Engaged with EuroHSP to develop the function of the European umbrella organisation
- Recommended to appoint two of our younger members as ambassadors for the group
- Updated our use of funds policy to allow appropriate payments to beneficiaries from specific fundraising events
- Commenced formalising the committee structure of the group
- Continued to update the group's website.

No proposals for research grants received this year were considered to be suitable for the CIO to support, and funds have been carried forward until such suitable research projects arise.

Research grants would typically be made up to £10K or for up to £10k per year perhaps with a commitment for 3 years (to support a PhD student). We are ready and able to make such a research grant next year.

Financial Review

Income: £27,788.89
Expenditure: £21,201.68

There was a surplus of £6,587.21 for the year.

At the end of the financial year (30/4/2018) the Group has net assets of £ 41,039.83 held in its bank accounts.

All monies raised for research after collection costs (£ 5,140.27) were assigned to a restricted account and were used towards medical research at Exeter University.

There are no outstanding liabilities. The Trustees consider that the Group is financially sound. The trustees consider a reserve of around £15,000 should be held to meet contingencies.

John Mason
Treasurer

Adam Lawrence
Chairman

Date: 29 June 2019