

**HSP SUPPORT GROUP:
ANNUAL GENERAL MEETING MINUTES:
Saturday 13th July 2019
Tally Ho Conference Centre, Pershore Rd, Birmingham.**

1. **Apologies for Absence** were received from: Angela & Tony Barnicoat, Melanie Burnside, Steph and John Flower, Colin Haines, Angela & Neil Blencowe, Ann Synes, Steve & Jan Bavister, Christine Lilley, Andy Barrett, Michael Jarvis, Irena Pritchard, Mike & Liz Booth, Ian Clarke, Shirley & Juliet Bessent, Brooke Wyatt, Maurice Charge, Carol Rowe, Robert Turner, Jacqueline McLaughlin, Mark Tomlinson, Lynn Hamblin, Anne Taylor, Patricia Du Pontet, Matt Harmer, John Moule, Paul Eccleshall.

60 people attended the meeting.

2. The **Minutes of the 2018 AGM** were agreed to be a true record. They were accepted by a majority of members present without comment.

3. **Chairmans Report**

Adam provided a summary of the group's activities since the last AGM:

At last years AGM we agreed to adopt a new Constitution, declaring ourselves to be a Charitable incorporated organisation (CIO) governed by our members.

Since then we have developed our mission statement and procedures, and have registered our new status with the Charities Commission. It is clear that as we grow and develop we will need additional help to keep the organisation working well.

Adam gave thanks to all members over this period, particularly mentioning:

- volunteers who have given their time
- all those who had done fundraising activities over the year
- researchers who were helping to understand our condition.

Activities in the future:

- An upgrade to our web site
- Setting up committees to run aspects of the Group
- Influencing the direction of reseach
- Widening our knowledge, spreading the word

Key Items from Last Year AGM workshops:

- Mission Statement and procedure development
- Make sure needs of younger people are considered
- Develop new activities
- Form links with other organisations

Mission Statement. We have developed a Mission Statement which has now been approved by trustees. We have developed a Research Grant application procedure which we will be trialling soon.

Younger people involvement/activity is still ongoing work for us.

Activities – we have agreed to support the cost of the meeting rooms for local meetings.

Other Links and Widening knowledge. Adam has made individual representations to get HSP Group recognised as a stakeholder in the developing guidelines for Cannabis use. There is also a "Physical activities in Rare Conditions" project in progress and again, Adam is representing HSP. The end of the current phase is due soon and Adam will report back to us.

Euro-HSP we are looking to develop links with them the and see how it is running – looking to have some voice @ European level.

4. **Trustee's Report:**

Copies of the Trustee's Report had been placed on each table. Dave Harris will highlight the main points.

The text of the report is included below:

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

Acceptance of the Trustee's Report and accompanying summary was proposed. The report was accepted by a majority of members present.

5. Financial Accounts

John Mason presented the Financial Accounts for the year which had been distributed amongst the tables. He outlined the main panels and gave explanations of figures contained therein.

John thanked Sonya Mason and Chris Harvey for their help over the course of the year.

There were no questions. The report was accepted by a majority of members present.

6. Secretaries Report

Trustee Meetings:

Since the last AGM there have been two meetings: 18th July 2018 and 19th February 2019.

HSP Support Group charitable status.

Since our AGM last year we have registered HSP Support Group with the Charity Commission as a CIO Association in accordance with the Constitution adopted at the AGM.

Member Grants:

Over the year eight grants to members have been approved. One further applications has been made which was turned down as being outside the scope of our scheme.

Research grants:

We have paid the third and last £10,000 instalment for the PhD student at Exeter.

Other Payments: A donation of £2000 was made at the Potato Pants festival. This money was raised at Tesco, Blandford Forum and we were asked to use it to support people in the local area. We have recently been able to fulfil that obligation by making payments to help two people within 30 miles or so of that location.

Helpline calls:

Stephanie has decided that it is now time for her to step down from the Help Line role. We are considering what the group should do in the future as much more on-line help is now available.

7. Membership Report

8. Election of Trustees:

Two Trustees, Ian Bennett and Dave Harris are prepared to stand for a further one year term. Della Brookman is stepping down.

Ian Bennett was re-elected by a majority show of hands.

Dave Harris was re-elected by a majority show of hands.

9. Any Other Business.

Mike Cain reported that he had attended a reception to mark Rare Disease Day on the terrace of the Houses of Parliament. He was able to talk with the head of Genome England (Mary Bythel) and was very pleased to hear the Minister of Health (Baroness Nicola Blackwood) explain to the assembled group, that included the All Party Groups, at length, what HSP was.

There being no further business the formal part of the AGM was closed at 1100.