

**HSP SUPPORT GROUP:
ANNUAL GENERAL MEETING MINUTES:
Saturday 4th July 2020
Virtual meeting hosted via Zoom.**

1. **Apologies for Absence** were received from: Leslie Brennan and Jane & Philippa Burrell.
At maximum, 67 people attended the meeting.
2. The **Minutes of the 2019 AGM** were agreed to be a true record. They were accepted by all members present.

3. **Chairmans Report**

Adam's summary of the group's activities since the last AGM would be under the following headings:

Activities as usual:

- Welcoming new members to the group
- Meetings
- Member and researcher grants
- Newsletters
- Website and social media
- Attendance at HSP and Rare Disease meetings

New Activities:

- Digital Meetings!
- David Pearce bequest
- Committee Structure
- New website

Help is needed

There are various opportunities to help the Group further its work for members. We were not restricted in who could volunteer for these tasks. Indeed we welcome people from outside the group. Members friends and family, other professionals with an interest in HSP could all be considered to join as Trustees or committee members or for other work.

Thank You!

It was important to recognise and thank all those who had contributed to the group during the year:

- **Members**
Without members we wouldn't be here
- **Volunteers**
Their valuable time makes this group work
- **Fundraisers**
Activities raise funds and awareness - Amazing!
- **Researchers**
Their work gives us hope

Coronavirus

To comply with the guidelines we have adapted as follows:

- Stop our face-to-face meetings
- Virtual meetings using Zoom
- Allows us to have meetings without leaving home!

Meetings

Mike Cain and Adam had between them attended:

- House of Commons - London
- Rare Disease Showcase - Manchester
- Spatax international conference – Nice, France
- EuroHSP meeting – Vienna, Austria
- Mike Cain 'attended' European Rare Disease conference held online from Stockholm
- (Newslink January 2020 covers most of these)

Our new website is live!

Thanks to Jenni Preston for developing this for us. Members are encouraged to visit it, browse around it and see how it works.

If you spot anything which you think is missing or could be further improved, please tell us!

Social Media

Increasing our presence:

We have groups present on FaceBook, Twitter and LinkedIn – why not follow us there?

Honorary Members

At present the group has almost 100 honorary members who are in the main drawn from health professionals, we'd like to further extend this as a way of maintaining awareness of the group and the condition. We are pursuing this idea in the following ways:

- Reaching out to healthcare professionals
- Quick survey on Facebook groups – Writing to neurologists
- Presenters at AGM/meetings
- Research grant applicants
- **Ask your specialists...** Members can help here by asking their specialists about becoming Group Honorary members.

David Pearce

Bequest

We had received a substantial amount from the estate of David Pearce, one of our former chairmen. With help from Ian, who knew him well, we have carefully considered David's approach to life and to the running of the group. This has guided our approach to using this money in ways we believe he would have approved of:

- Meetings costs – now include refreshments
- 2021 AGM will be free of charge
- Half member costs paid for Calvert Trust bookings
- Maximum research grant value increased to £15,000
- Award for fundraising
- Award for raising awareness of HSP

Award for fundraising

This year, the award is given to Peter Bateman who over the period 2011 to 2019 raised over £10,000 for the group. He did this by providing HSP Group customised key rings and pens together with collecting boxes at hotels and golf clubs etc. near where he lived, his regular replenishment and cash collection no doubt helped in delivering this fantastic amount for us.

Award for raising awareness of HSP

This award is given to Lily Rice who has used her situation to great advantage in becoming the first European person to complete a wheelchair backflip. She has become a mentor to other young people who are coming to terms with life in a wheelchair and uses these opportunities to raise understanding and awareness of the condition and of the Group. Lily was on BBC1 a couple of weeks ago, and I encourage you to watch her episode of Our Lives, Defying Gravity on BBC iPlayer.

Ambassador

Amber Meikle-Janney. Last year at the AGM we made Amber our first ambassador for the group, and Amber was really pleased about this. Since the AGM Amber has had one or two health issues which means that she's not been as able to do as much as she would have liked. However, Amber also works with the charity Back-up, which helps people with spinal cord injury. Amber teaches wheelchair skills, and when working for the charity has an honorary spinal cord injury herself – and recently she got to run some of these sessions at the Calvert Trust. These courses are great because they help people do more with their wheelchairs, and it helps people to see them as a benefit more than a burden. Amber's other passion is crocheting woolly hats, and she treats her hamster like royalty. We look forward to hearing what the next year holds for Amber.

Committee Structure

We have developed the committee structure along the lines set out at last years AGM:

Research Committee (Chair Adam Lawrence)

- Assess research funding applications made to the group
- Understand research being carried out
- Identify gaps in research

Fundraising Committee (Chair Rachel Mortimer Holdsworth)

- Seek new funding opportunities
- Coordinate existing fundraising
- Promotion of fundraising activities

Meetings Committee (joint Chairs Hilary Croydon and Jane Bennett)

- Run the groups meetings
- Support/coordination with meeting organisers,
- Identify new locations for meetings

Membership Committee (Chair Ian Bennett)

- Welcome new members and help existing ones
- Maintain membership database
- Annual membership renewals

Research Grants

We received three grant applications recently and have used our newly developed assessment procedure to successfully evaluate them. We have been able to provide funding for all 3 applications received:

- **University of Exeter** – PhD student working on biomarkers, aiming to develop a predictive HSP blood test, applicable to all types of HSP.
- **University of Sheffield** – PhD student working on biomarkers and gait analysis for SPG7, aiming to develop predictive measures.
- **Institute of Molecular Biology and Pathology, Rome** – Work on predictive biomarkers for SPG4

Looking for help

We are looking for help!

- New page with specifics on the website
- Key focus: succession for Secretary and Treasurer
- You don't have to be a member
- Happy to chat to anyone interested!

4. Treasurers Report

Financial Accounts

John Mason presented the Financial Accounts for the year which had been published on our web site. He outlined the main panels and gave explanations of figures contained therein.

Income:

Subscriptions	4,286.50
Donations and legacies	5,126.19
David Pearce bequest	86,704.79
General individual fundraising	9,681.28
Conference	585.00
Restricted fundraising	886.10
Total income	107,269.86

Expenditure:

Administration costs	650.97
Trustee expenses	2,186.10
Conference, Meetings, AGM	2,701.00
General fundraising expenses	1,912.96
Newsletter	756.46
Grants to members	3,117.98
Restricted fundraising expenses	23.81
Total expenditure	11,349.28

Balance sheet:

Balance at 1st May 2019	41,039.83
Income	107,269.86
Expenditure	11,349.28
Surplus in 2020	95,920.58
Balance at 30th April 2020	136,960.41
Allocated to general fund	136,098.12
Allocated to restricted fund	862.29

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

A question about investment was raised via Chat. This was responded to after the meeting by email.

The report was accepted by all members present.

5. Secretaries Report

Trustee Meetings:

Since the last AGM there have been four meetings, three of which have been virtual meetings hosted on Zoom.

Member Grants:

Over the year four grants to members have been approved. In total these awards amounted to £3117.

6. Membership Report

Ian showed a map illustrating how members were distributed across the UK.

We at present had 340 paid members and 98 honorary members. He would be following up lapsed members over the coming weeks.

We now have a new membership committee which comprises of myself, John Mason and Mitesh Patel. Mitesh will be gradually taking over my role as membership secretary and we aim to complete this process in a couple of months' time.

Remember to let us know of any changes of contact details so that we can keep our records up to date. If your subs are overdue, please arrange payment. Also, if you currently receive your newsletter by snail mail but would be happy to receive it by email, please let us know as this saves us money. Talking of the newsletter, thanks for all the amazing contributions from the past. Please keep them coming in.

7. Election of Trustees:

Two Trustees, Adam Lawrence and John Mason are at the end of their present term and are standing for re-election this year. Mitesh Patel is standing for election for the first time.

Adam Lawrence was re-elected by a unanimous vote.

John Mason was re-elected by a unanimous vote.

Mitesh Patel was elected by a unanimous vote.

8. Any Other Business.

Presentations

Adam reminded us that on-line presentations will be given as follows by speakers we had arranged for this AGM:

- Saturday 1st August - Dr Channa Hewamadduma: Hereditary spastic paraplegia: insights from a large regional cohort of patients
- Tuesday 11th August - Dr Gita Ramdharry Gita will be talking about the Physical Activities in Rare Conditions project which Ian and I have had some involvement in, and where that is going in the next stage. She will also cover more general aspects of rehabilitation and the importance of physical activity for those of us with HSP.
- Saturday 25 July - Prof Andrew Crosby and Dr Emma Baple are going to be talking about their work on cholesterol processing which was published in the neurology journal, Brain last year, which came from a PhD which we part funded and from their historical studies that led to this. They will also talk about their plans for the future that we're also supporting, both with you offering to take part in studies and through our funding towards another PhD student
- Calvert Trust – to be confirmed soon – our contact there has been furloughed.

There being no further business the formal part of the AGM was closed at 11.11am.

The Zoom meeting was kept open to provide members with a platform for free-ranging discussion. The meeting drew to a close by midday.

Dave Harris, Secretary. HSP Support Group

4 July 2019