

**HSP SUPPORT GROUP:
ANNUAL GENERAL MEETING MINUTES:
Saturday 16th July 2022
Virtual meeting hosted via Zoom.**

1. **Apologies for Absence** were received from: Tony Richardson, Melanie Burnside and Andy Barrett.

At maximum, 37 people attended the meeting.

2. The **Minutes of the 2021 AGM** were agreed to be a true record. They were accepted by all members who voted.

3. **Chairmans Report**

Adam's introduction set an expected time of 40-45 minutes for the meeting and reminded members of the ways that Zoom would be used.

Adam delivered a summary of HSP and it's effects as an aid to those who in future would watch a video of the meeting.

Our Mission Statement:

**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:

In a similar way Adam described the HSP Support Group for future viewers.

Meetings

The meetings committee is the group of those people that organise our meetings. They give support to meeting organisers and look into new meeting locations.

We have been very happy to re-establish face to face meetings, with some already taking place this year. The decision to have face-to-face meetings sits with each meeting organiser. New meetings have been arranged in some areas, initially by Zoom. Our monthly Zoom meetings for all members have remained popular, and we are pleased that we have started Zoom meetings for families – which tends to cover families with younger children, and have also started meetings for families where someone has SPG11 or SPG15, tends to cover families where the affected person is an adult.

The committee have created some more pages on our website which cover more of the details of meetings, and I'd like to thank all of our meeting organisers. The work you do is excellent, and the meetings form a vital part of our support community. As I mentioned last year Hilary is stepping down as Chair of this committee and we're still keen for someone to come forward and think that they could helping co-ordinate our friendly group of meeting organisers.

Research

Next we turn to the research committee. There have been no new applications for funding for research projects this year. We recently sent out the second edition of our newsletter for researchers to help develop our links with this community.

Following on from last year we had another student, Malaika, write an HSP essay for the 2021 student voice award, but unfortunately, they were unsuccessful.

Another new activity last year came through our membership of EuroHSP. Discussions there with the Tom Wahlig symposium led to EuroHSP sponsoring an award for research projects into HSP which look into treatments and similar aspects of HSP. Each of the EuroHSP members made a contribution to the award prize fund, and we're looking to do

the same for this years symposium. There were 8 papers submitted for the award last year, and the winning paper was in fact the Italian study which we part funded last year.

Cardiff

Two students elected to select projects to do with HSP. Once they have started these projects we can share details of how you can take part. Firstly, I'm pleased to introduce Sidney to introduce herself and her project. A short introduction was then delivered by Sidney Choi.

The second student is Jovana. Her project is about exploring the benefits of stretching exercises for people with HSP. Jovana will be seeking to interview members to hear your views on how well stretches help you manage your HSP and your wellbeing.

Other Projects

You may recall that we've agreed funding to support two students researching into HSP. At Exeter Nikol Voutsina is using cutting-edge gene editing methods to target and deactivate HSP genes in cells in the lab, to develop laboratory models of HSP for a wide range of studies. Olivia, the previous student sponsorship's work has helped establish methods for work to study fat processing pathways inside cells, where abnormalities are believed to cause HSP. They are also undertaking genetic studies to identify new types of HSP and develop new testing approaches.

At Sheffield Inga Gumienna is about to start, with the research work so far being carried out by other team members. They have used MRI scans to identify novel signal changes associated with SPG7, which has then been validated in a larger cohort of people. They have also characterised the cognitive impairment side of SPG7 in a larger cohort of people, which improves the baseline knowledge about this.

4. Web Site Committee (Dave Harris)

A new committee has been set up this year to manage our website. We had our first meeting in July. Our main aims are to:

- Ensure the website is available to readers. Maintains the software on the servers and manages the necessary payments, security and operating costs.
- Liaise with other committees for website content. This activity is to ensure the site remains current and reflects what HSP group does.
- Ensure website accessible on current browsers/devices. Much of the detail of this is supported by the software which is run on the site which is a widely used product called Wordpress.
- Control of group documentation held on website server. Ensuring that documentation of meetings, and other items relevant to the organisation and to HSP (eg lists of SPG genes) are maintained.
- Control membership database held on website server. Ensuring that the details we hold about our members are kept in a secure way and are appropriate.

5. Membership Committee (Mitesh Patel)

Mitesh reported we now have 367 active members, together with 89 honorary members. The group has recruited 24 new members this year so far. There are ongoing efforts to help members with children set up links with each other.

6. Fundraising

Adam gave a big thank you to everyone who has supported the group throughout the year with donations and all sorts of fundraising activities. He illustrated several other ways of raising funds:

- There are also a few people who donate money through their salaries each month tax-free through give-as-you-earn schemes set up through their employers.

- Estelle Hetherington is running the London Marathon this year to raise money for the group. Her dad has HSP, and we're delighted that she's thought to raise money for us.
- There are some easy ways that members can raise money for the group. For example, if you're taking part in events where you're getting sponsorship you can let us know, and we can promote those on our social media channels.
- Our other fundraising channels remain open - those who use Amazon can switch to the Amazon Smile app and easily raise money for the group using their normal amazon account at no cost.
- Alternatively you can use EasyFundRaising, which installs a toolbar in your browser and triggers donations from many popular retail outlets, also at no cost.
- We also have a page up at Just Giving for other donations of any kind.
- **1000 Mile Challenge.** The 1000 mile challenge, launched last year, was a great success and I'd like to thank Rachel whose amazing idea this was. As you can see, 46 people travelled the equivalent distance from Lands End to John O'Groats, back again and a little bit further! Overall this event raised us £6388 pounds. Thanks to everyone who took part in this event and raised some money for us.

Around 20 different modes of transport were used, which range from walking with and without sticks, a full range of manual and electric wheelchairs and mobility scooters and onto two and three wheeled bikes, some powered by pedal, some by hand and some electric. Miles were logged by horse, canoe, paddleboard and by water-ski! A few also submitted miles from indoor activities like swimming and from using exercise machines. This illustrated that even though we have a rare disease which affects our mobility, we can still keep healthy, have a good time and demonstrate that we can get about where we want to.

Potato Pants

Last year Ian Bennett organised a virtual potato pants festival, well I am pleased to let you know that the potato pants festival is returning as an in person event this year, and I'm now going to hand over to Ian to tell us some more about this.

Ian first explained that the name comes from an HSPer who first explained to a friend that HSP felt like walking with your trouser legs filled with potatoes. It has since been used all over the world and Ian decided to use it for our music festival.

Event started in 2015, missed two years due to Covid, now moved to a new more suitable venue. Musicians play for free. The event raises significant sums for HSP.

Hoping many will turn up to support the event 6-7 miles outside Bournemouth. Please "share" it to help us get more people. Last few bands play indoors (noise), but the main daytime event is outdoors.

Social Media

This page gives you the statistics for our YouTube channels, which shows that overall we've had about 5000 views of our videos. I'll be adding to that by uploading the video of this AGM in the next couple of days. [2021 viewings: AGM 166; Presentations 659; Other Videos 553]

Here's a quick reminder of our social media channels, facebook (+243), twitter (+61), linkedin (+5), youtube (+57) and we started an Instagram (+171) channel to be able to show some of our 1000 mile stories. The numbers in brackets are the increases in followers for each channel from last year.

Looking for Help. Adam said this:

"This page is very similar to one I put up last year. A few people have seen this and been in touch but we still need more help. Of note for the coming year, we need to get a new treasurer and a new secretary. Dave reached the end of his term this year and has

agreed to stand for another year as we've not found a new Secretary. Also we need a Chair of our meeting committee. We have a volunteer Shanake, who has offered to help in the Treasurer role and is in discussion with John. If all goes well we will have Shanake as a candidate at next years AGM."

7. Secretary's Report

Trustee Meetings:

Since the last AGM there have been three online meetings: 24th August 2021, 7th December 2021 and 3rd April 2022. Emily Bell was co-opted as a Trustee at the April meeting and stands to be elected at this AGM.

Member Grants:

During our last financial year AGM fifteen grants to members have been approved. This larger number than usual is probably reflective of the Covid pandemic and the average over the last three years is similar to pre-Covid years.

Research grants:

No new grants have been approved during the year.

Enquiries via Web Site:

Enquiries continue to arrive steadily with the web site generating new requests every week. This year we've received over 75 enquiries since the last AGM.

Thanks again to member Jenni Preston who maintains the site for us

8. Treasurers Report

Financial Accounts

Income, Expenditure and Balance Sheet for the year are shown in Summary.

Accounts are published in full on the web site and with the Charity Commission.

Income:	
Subscriptions	5,023.00
Donations and legacies	10,532.07
Fundraising activities	17,187.14
Total income	32,742.21

Special mention in Fundraising for Peter Bateman who still sends in donations each year.

Expenditure:	
Grants to members	12,062.44
Grants for research	15,000.00
Meetings, AGM	45.00
Trustee expenses	120.24
Newsletter	209.17
Administration costs	1,625.12
Fundraising expenses	530.10
Total expenditure	29,591.97

Administration costs include items such a Zoom licences (used by this AGM), Awards funding, subscriptions to national and international organisations e.g. Neurological Alliance, Audit Fees and costs of the web site.

Balance sheet:	
Balance at 1st May 2021	129,215.74
Income	32,742.21
Expenditure	29,591.97
Movement of funds	3,150.24
Balance at 30th April 2022	132,365.98
Allocated to general fund	132,365.98
Allocated to restricted fund	0.00

The Group is in a good state of financial health generally.

THANKS My thanks are due to Sonya Mason for her work on the accounts throughout the year and to Chris Harvey for examining them. Both gave their time generously and without cost.
John Mason, Treasurer

9. Voting Results

This year, we followed the same arrangements as last year, making our voting accessible to more members using both postal and electronic voting. Overall 78 members cast votes, which is similar to last year, just over 20% of our membership. Adam encouraged all members to take just a few minutes and use their votes to let us know what they think.

The minutes, the accounts and the report were all approved unanimously.

10. 2022 Awards:

Raising Awareness Award.

Our raising awareness award this year goes to Estelle Marshall. Our regulars may recall that we awarded Estelle with the fundraising award last year, which means that she is the first person to win both of our awards!

Estelle has been making people more aware of HSP on quite a few fronts, on the Meetings front she has been instrumental in seeking out a new venue for us to be able to hold meetings. Estelle has also been using her physiotherapy experience to be able to help others understand the needs of people with HSP. Estelle has been sharing her experiences in the Facebook HSP groups to help share her knowledge and experiences with others.

I'd like to thank Estelle for all the work and commitment she puts into the group and for all that she does to raise awareness of HSP.

Fundraising Award

Our fundraising award this year goes to Tom Bell.

Tom's father in law has HSP, and Tom had been in touch with the group to get some advice and support when his wife was getting tested got HSP. Tom found our advice and support really useful, and he decided to return the supporting favour. He challenged himself to run 17miles of an 11th century march whilst wearing full Viking battle gear in order to raise money for us! Tom raised £4157 which is an amazing amount of money.

I'd like to thank Tom for such an epic way or raising so much money for the group.

11. Trustee Election.

Dave Harris. (Elected - 99% of 76 votes cast) This year Dave came to the end of his 3 year term. As I mentioned earlier, Dave has offered to stay in his role of Secretary for another year, and so offered to stand for re-election.

As you can see Dave gets a clear majority and is re-elected as a trustee, and I look forward to working with him going forward, hopefully being able to hand-over to a new secretary in the coming months.

Emily Bell. (Elected – 100% of 75 votes cast). We co-opted Emily Bell as a trustee in April, and she is up for her first election, and was unanimously elected as a trustee. I'm

looking forward to working with Emily and discussing her ideas and perspectives about the group.

Trustees 2022-2023:

Adam Lawrence; Mike Cain; John Mason; Dave Harris, Mitesh Patel; Emily Bell

Everyone is carrying on in their roles with John being treasurer, as already mentioned Dave being secretary and Mitesh being membership secretary. I am also pleased that Shanake is interested in becoming treasurer, and we are looking forward to co-opting him as a trustee with a view for his election here next year. I thank all for their excellent work, and look forward to us moving the group forwards in a co-ordinated fashion.

12. **AOB** – Nothing Raised

13. **AGM 2023**

I know that few of you were disappointed not to have a face-to-face AGM this year. I hope that with our gradual return to face-to-face meetings you're able to find one near you. We felt that there may be some benefit in having a national social meeting, and we have moved our previous AGM booking date to Saturday 8th October and are proposing to re-badge as a social event. I'd be very pleased to hear from anyone as to what we could do for this social day, and hopefully help with sorting this out. In keeping with making our AGM as accessible as possible it is most likely that we'll be back here next year by Zoom and then up on YouTube, with a provisional AGM date of Saturday 1st July 2023.

Presentations – via Zoom

At the moment I've got four talks lined up for the summer. There are still a couple of dates to sort out and details to confirm, but this is the latest information that I have. Firstly, I'm in conversation with Ian Marsden to talk to us. You may remember that Ian was in the GB Paralympics team last year in the canoe. Ian has HSP and I'm hoping that he will be able to join us to talk about his experiences.

Next, I have been in touch with the **Citizens Advice Bureau** who are going to talk to us on **Wednesday 10th August at 7pm** to give an overview of the different benefits which people with HSP may be entitled to get.

Later in August we've got **Andrew Crosby and Emma Baple from Exeter** back to talk to us and give us the highlights of Olivia Rickmans PhD which we sponsored a few years ago. They will be talking to us on **Wednesday 24th August at 7pm**

Lastly, Citizens Advice were also keen to be able to talk with us about energy support, grants that may be available and other aspects of energy efficiency in these times of rising prices. I've not arranged a date for this to happen yet, but am hoping to be able to do this in early September.

We will follow the same form as the last 2 years, with presentations via Zoom with the opportunity to ask questions after, and I'm working on getting everyone's agreement to put these on our YouTube channel. Once we have dates sorted we'll e-mail details around with Zoom links and the finalised dates and times. I hope to see many of you there!

Meeting Close

There being no further business the formal part of the AGM was closed at 11.20am.

Dave Harris, Secretary. HSP Support Group

3 August 2022