

**HSP SUPPORT GROUP:
ANNUAL GENERAL MEETING MINUTES:
Saturday 15th July 2023
Virtual meeting hosted via Zoom.**

1. **Apologies for Absence** were received from: Katie Brennan, Anne and Fergus Palmer
About 50 people attended the meeting.
2. The **Minutes of the 2022 AGM** were agreed to be a true record. They were accepted by all members who voted.
3. **Chairmans Introduction**
Adam said we took the decision to keep our AGM virtual to allow our members who have difficulties travelling to attend. We asked our members about this decision, and he intends to discuss this later.
Adam set an expected time of 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. He then reminded members of:
 4. **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.**
5. **The Group.** The support group is a registered charity, and all the work that is done for the group is done on a voluntary basis. Our main area is providing support to those with HSP, which we do by sharing stories and information and by awarding grants to members to help purchase equipment. There are three main ways we create our community, by meetings, through our newsletter and on our website. Meetings can be groups of any size, from 2 meeting up in the pub through to our largest event, the AGM. They can have presentations or just be an informal chat. We're keeping a mix of virtual meetings on Zoom and face to face meetings so that we can satisfy those members that prefer to meet up and chat in person and at the same time be open and accessible to as many members as possible.
6. **Meetings Committee.** 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've been pleased to carry on with our face to face meetings, but attendances at these are lower than they were pre-Covid. We have new face-to-face meetings in Burnley (Lancashire), and new Zoom meetings for parents of children with HSP. We also have a new meeting organiser for Norwich. Ian's monthly nationwide Zoom meetings remain popular, and we've continued Zooms for; Scotland, Wales, and SPG 11 and SPG 15 families. Our Revised Welcome Pack is being used for ideas and support. We're still looking for help, specifically, a chair for the committee, a host for our meetings of parents of children with HSP, and meeting organisers in areas not yet served.
7. **Research Committee.** It has been a quiet year. There has been one new application for funding for a research project, which we are still evaluating. Similar to the last couple of years we had another student, Ela, write an HSP essay for the 2022 student voice award. We have made another contribution to the most recent EuroHSP sponsored award given at the Tom Wahlig symposium. The 2022 award went to a German team looking at gait sensors to measure mobility. I have previously mentioned the two Masters students at Cardiff studying HSP for their dissertations, which several of you took part in. They have both very recently finished their studies, and we will hear from them later in the year.

8. **Ongoing Projects.** You may recall that we've agreed funding to support two students researching into HSP. At Exeter, overall progress with the research is very good! They have identified more detail on their recently discovered TMEM63C gene – relevant to cellular lipid (fat) processing, which are important for the normal function of motor neurons. Hopefully this leads towards knowing the root cause of HSP. They are also undertaking studies on two other genes which may be relevant to HSP, and if so can be added to the gene testing panel for HSP. Also, they are working on developing a new biomarker blood test for HSP. There have been various challenges with this work, and they hope to be able to offer this to people soon. They have sent me an update on their progress which I will email round to members soon. At Sheffield, the start point of the studentship has been delayed, although the team have been carrying on with research in the mean time. They have been using multi modal MRI neuroimaging studies of 40 people with SPG7. These results have led to the identification of a novel cerebellar locus which can account for cognitive changes in people with SPG7. Also, they have been working on gait monitoring using wearable sensor systems for people with HSP (both SPG4 and SPG7). They have identified a simple sensor, and they have validated this to be able to generate gait biomarkers for people with HSP.
9. **Web Committee.** A new section has been added to the website called “Living with HSP”, which is available on the top menu. This section contains a load of useful information, including thoughts on talking with your GP, different practical steps you can take, and a few considerations when choosing mobility aids. For those of you who have been members for a long time, this information is similar to that which was included in our old information booklet. Various changes to documents and processes have also been managed/ implemented in the period.
10. **Membership Committee.** We have members in the majority of counties in England, fewer members in Scotland and Wales, and none over in Northern Ireland. The number of active members is slightly down on this time last year. We're also looking to be able to put new members in touch with their local meeting organiser, to help develop networks. “Active members” means those who have already paid their subscriptions this year – when we looked at this the other week there were about 70 who hadn't paid, so please treat this as a gentle reminder, and definitely get in touch with us if you're having problems paying.
11. **Fundraising Committee.** A big thank you to everyone who has supported the group throughout the year with donations and all sorts of fundraising activities. Some examples of fundraising from last year, were Ray's music day, and both Estelle and James's marathons, which all raised good amounts of money for the group, and helped raise awareness of HSP to others. Others who are raising money this year, are Nick who has HSP, and is running several events this year, and has already raised a good level of money. In a very different way to raise money, Emma Lievesley is running a Minecraft tournament in a couple of weeks time in Rainford, in Merseyside. There are also many many others who have raised money doing a whole range of other things, and we thank them all. In our last two examples, there are other big adventures being planned. Jason and Gavin are trekking to Everest base camp, and Emma is going dog-sledding in Sweden, both early next year, and both raising lovely amounts of money.
12. **Potato Pants.** The potato pants festival, organised by Ian Bennett raised just over £2000, and the festival returns this year on August 26th. Ian Bennet then gave a description of the festival, stressing that its new location at the Cobham Social Club in Wimborne provided a much more wheelchair/ disability friendly environment that the previous venue which was on a farm.
13. **Secretary's Report.**
Trustee Meetings: Since the last AGM there have been four online meetings: 23rd September 2022, 24th November 2022, 23rd January 2023 and 18th May 2023.
New Trustees: Shanake Amarasinghe was co-opted as a Trustee at the November 2022 meeting and stands to be elected at this AGM. He is taking over the role of Treasurer from John Mason.
Juan Vasquez Ruiz was co-opted as a Trustee at the January 2023 meeting and stands to be elected at this AGM.

Member Grants: During our last financial year AGM nine grants to members have been approved.

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 65 enquiries since the last AGM.

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

14. Treasurers Report.

Income this year as show in table below:

Income:	
Subscriptions	5,128.00
Donations and legacies	5,859.56
Fundraising activities	8,439.89
Total income	19,427.45

For comparison, income in 2018 was 28K, so income down on what it was 5 years ago, John believes this is down to post-covid societal effects – less people going out etc.

Expenditure:	
Grants to members	6,409.99
Grants for research	15,000.00
Meetings, AGM	2007.66
Trustee expenses	311.22
Newsletter	760.84
Administration costs	1,752.68
Fundraising expenses	225.61
Total expenditure	26,468.00

Expenditure in excess of income, this has come out of our reserves. Explanation of restricted vs general funds given: when donations are asked to be used for research purposes they are accounted via the restricted fund so we can ensure they are so used.

Thanks to Sonya Mason and Chris Harvey (Examiner) for their work both generously gave their time without cost to HSP Group.

15. Voting Results. We have followed the same arrangements as the last couple of years, making our voting accessible to more members using both postal and electronic voting, and from our YouTube questions I know that there are some members who have voted but who do not attend our AGMs. Overall 78 members cast votes, which is similar to last year, around 22% of our membership: Electronic votes 63 and Postal votes 15.

Minutes of the AGM accepted, 100% of 74 votes cast,
2022 Accounts accepted, 100% of 78 votes cast
2022 Trustee Report accepted, 99% of 78 Votes cast

Whilst this is a bigger turnout that we would get at a physical AGM, there is still a silent majority of members who have chosen not to vote. Next year, I encourage all members to take just a few minutes and use their votes to let us know what they think.

16. Annual Awards.

Our **Raising Awareness** award this year goes to Ian Bennett.

Ian has been running the potato pants festival for quite a few years, making HSP part of his local music scene. There are many bands and their fans who now know about HSP, along with others in local area who hear about the festival through local reporting.

I'd like to thank Ian for all the work and effort which goes into getting the festival together each year, it is no mean feat, and it is brilliant to see the awareness of HSP raised in such a great way through a broad cross-section of the community.

Ian accepted the award and described the origin of the potato pants idea, he also stressed that although it was mainly a local event in Dorset, all attendees and participants were given a good idea about HSP and its effects, thus broadening more general understanding of the condition.

Our **Fundraising Awareness** award this year goes to Estelle Hetherington.

Estelle's father has HSP and Estelle fundraises mainly because of this connection. Adam expressed his thanks and appreciation of her efforts. Estelle gave thanks for the recognition and said that running for the benefit of a charity spurred her on.

17. **Trustee Elections.**

Shanake Amarasinghe. We co-opted Shanake Amarasinghe as a trustee in November last year, and he is up for his first election. He been elected as a trustee with 96% of the 74 votes cast and I'm looking forward to working with him. Shanake said he had been shadowing John for the last year and had several years experience as an auditor. He was looking forward to performing the Treasurer role for us.

Adam Lawrence. Adam has come to the end of his three-year term for the group and was pleased to have been re-elected with 97% of the 77 votes cast. He was pleased to have been re-elected and will continue to work to his best for the group.

Mitesh Patel. Mitesh has also come to the end of his three-year term for the group and Adam was pleased that he has been re-elected with 99% of the 74 votes cast. He looked forward to continued working with Mitesh to welcome new members and help existing members get the most out of the group.

Juan Vasquez-Ruiz. We co-opted Juan as a trustee earlier in 2023, and this is his first election. He been elected as a trustee with 99% of the 73 votes cast. Juan thanked members for their trust in him and looked forward to working for the group.

Adam then summarised John Mason's history as Treasurer of the group, and thanked him for that past work. He also noted that he had valued John's inputs to the management of the group as well as his work as treasurer.

18. **AGM.** I know that few of you have been disappointed not to have a face-to-face AGMs since the coronavirus pandemic started. To help us understand the views on this we asked members about if they preferred a face-to-face AGM or virtual. I deliberately did not include an option for hybrid AGM because this would be an easy choice for everyone to select without thinking about it.

As you can see, the results of the voting members are split with about a third wanting face-to-face and two thirds wanting virtual. I was expecting the split to be more in favour of the virtual AGM than this, and we will have discussions at trustee meetings to reflect on this. There is clearly desire for our AGMs to be stored on YouTube and promoted, so we also need to take that into account. Just for complete context, the costs of holding a hybrid AGM are expensive. We would need to use a venue who is able to provide the various cameras and microphones that we would need. We made a few enquiries last year, and at Tally Ho we would have to provide all the technology and run it ourselves. We asked two other venues who offered packages where they would stream our event, but these were coming in at around £2500. We would have to decide if it would be worth spending that much money given the different views expressed. I'm always welcome to hear from people about this, please drop me a line.

For next year we have a provisional AGM date of Saturday 13th July 2024.

19. **AOB**

a) **Phil Bungay.** Query about information re recent meeting – Adam would refer this to Mike Cain.

b) Enquiry re member grants from Lu Brown. Answered by Adam.

c) Member Grants publicity. IB asked if we might be able to arrange for next years Potato Pants festival the presentation of grant “on stage” to generate publicity interest.

d) Hande Ozdinier. Would like to make a donation. Link passed over via Zoom. Hande enquired about research co-operation with the Euro group to increase number of patients in research efforts. Adam agree to help progress this idea.

Meeting Close

There being no further business the formal part of the AGM was closed at 11.50am.

Dave Harris, Secretary. HSP Support Group

22 July 2023

Diary Dates for upcoming Talks/ Presentations:

Presentations – via Zoom

- Ela Curic – Sat 22nd July 09:00
The Diagnostic Odyssey (Student Voice Essay)
- Cinzia Rinaldo – Sat 22nd July 10:00
Spastin recovery in hereditary spastic paraplegia
- Channa Hewamadduma – August
Update on current Sheffield PhD sponsorship
- Ian Bennett – Sat 2nd September 10:00
Advice on selecting mobility aids
- Hannah Gilbert – Sun 3rd September 10:00
Compassion focused therapy