

**HSP SUPPORT GROUP:
ANNUAL GENERAL MEETING MINUTES:
Saturday 3rd July 2021
Virtual meeting hosted via Zoom.**

1. **Apologies for Absence** were received from: Zoë Gibson.

At maximum, 39 people attended the meeting.

2. The **Minutes of the 2020 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.

HSP: A summary:

- HSP stands for hereditary spastic paraplegia, which is an umbrella term. There are over 80 different types of HSP. It is a rare disease with estimates of prevalence around 3 in 100,000. Because it is rare healthcare professionals have not usually heard of it.
- The **main symptom**, affecting pretty much everyone, is spasticity or weakness in the legs, which deteriorates over time as the spine degrades and messages between brain and muscle are disrupted. There is great variation between individuals in the age at which HSP starts, in the speed of progression of HSP and how much it affect individuals.
- **Other symptoms** frequently occur, bladder urgency and frequency, pain and fatigue. The effects of HSP can vary from day-to-day with individuals, and there is a long list of other symptoms which can affect people.
- Given that **HSP is rare** getting a diagnosis can be challenging. There are genetic tests available for some types of HSP but not others. The early symptoms of HSP are similar to other conditions, and the progression of HSP in an individual is very hard to predict.
- Many **people with HSP often feel isolated**, lonely or depressed. Information about HSP is often hard to find, and some people find it hard to accept they have this progressive condition.
- **Right now there are no cures for HSP**. All of the available treatments are around symptom management. It is worth remembering that there are great teams of researchers working on HSP, increasing understanding and looking for potential cures.

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:

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**. You'll hear more about our website later, but our newsletter, Newlink comes out 2 to 3 times a year, and we're always keen to hear about members activities, stories and opinions. You can download these from 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. Since coronavirus we've also been holding this online. This talk of meetings allows me to move seamlessly into our first committee report, from the meetings committee.

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.

This year there have been new regional Zoom meetings which we hope will convert into face-to-face meetings once coronavirus restrictions are sufficiently lifted. There have also been national Zoom meetings, including one on Christmas Day, and we're also targeting some meetings to those who are feeling lonely or low.

The committee have prepared a wonderful **meetings guide** to help people start up a new group meeting in their area or digitally – I've read this, and it is fantastic! There have been a few new faces looking to set up meetings in their areas, and I thank them for doing this. Hopefully the welcome pack shares the top tips

and reduces the stresses of doing something new. Anyone with an organisational head who likes a jolly good natter is welcome to step forward and have a go at doing this. Lastly there are some updates to the meetings pages on the website being prepared.

I'd just like to finish by **thanking all of the meeting organisers**. The work you do is excellent, and the meetings form a vital part of our support community, and the committee seems to be working well. Finally, I'll thank Hilary and Jane who stepped up to be chair of the new committee last year, truly an in-at-the-deep-end experience! Hilary is stepping down as Chair of this committee and I'd welcome someone else to think about helping co-ordinate our friendly group of meeting organisers.

Research

There have been no new applications for funding for research projects this year. We have created a new newsletter for researchers to help develop our links with this community better. Mitesh made a call for students studying neurology and neurosurgery to help the group. The two key outcomes are Yuqi, who has made the highlights videos on our youtube channel, and Remi, who wrote an HSP essay for the student voice award.

Following a connection from Mike Cain, we've managed to get some HSP projects onto the final year thesis list for Masters students studying genetics at Cardiff, and hopefully in a year or two I'll be able to ask if you wish to help Sidney and Jovana with their studies to help us.

Research Updates

You may recall last AGM that I announced we'd agreed funding for three research projects. These have all been affected to some degree by Covid.

At Exeter the student is ready to start in August, and they will be looking to get families into the clinic later in the autumn. The team have been undertaking other relevant work which will be published soon.

At Sheffield they have a student lined up scheduled to start in September or October. Research fellows from other projects have been doing some of the activities for this project in order to maintain the momentum.

In Italy the research was carried out and the paper published. They identified a potential drug target, and I am seeking to find out more information about this.

Membership Committee

Mitesh reported we now have 356 active members, together with 96 honorary members. The group has recruited 18 new members this year so far. The honorary members include healthcare professionals from 33 UK institutions.

Fundraising

The key message is thank you to everyone who has supported the group with fundraising activities throughout the year. I know that the year has been tough for many, and we are delighted to hear that some people have made the special effort to raise money for us at this time. You will hear some specific details a little later when we get to the awards part of the day. Please note that we are happy to help supporting any fundraising ideas which people have.

Potato Pants

Before we leave fundraising I'd like to say a special thanks to Ian Bennett for organising a virtual potato pants festival this year. A fantastic time was had by all as we watched and listened to Amie, Mikey, Matt and Matt singing a lovely range of tunes. During the event the funds kept coming in, and I've taken the liberty of rounding the total up by a few pounds to call it a thousand pounds raised. This event was our biggest fundraising event of the year. I'm hoping that the festival is back to being face to face soon.

Fundraising Options

There are some easy ways that you can raise money for the group. Those that use Amazon can switch to the Amazon Smile app and raise money for the group using their normal amazon account and preferences and 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 and Virgin Money for other donations of any kind.

Other Activities

There are a few other activities which have gone on outside the remit of the committees.

As you know last year was our first digital AGM, marking the start of our digital journey. Since then we've got a YouTube channel where you can see our AGM and the subsequent presentations. I'll be uploading the video of this AGM in the next couple of days. There have been over 360 views of last years AGM, over 1300 views of the three presentations from last year, and over 600 views of the highlights and Q&A videos which Yuqi has made for us. We held our first awards here last year, and you'll get to see this years awards soon.

Looking for Help

This page is very similar to one I put up last year. A few people have seen this and been in touch, which is brilliant. We still need more help. Of note for the coming year, we need to get a new treasurer and a new secretary as John and Dave have both said they wish to stand down next year at the end of their terms, and Hilary is stepping down from Meetings committee chair.

It would be brilliant to have more diverse opinions at our trustee meetings. Us trustees are all men, and not as young as we used to be. It would be wonderful to hear from parents of children with HSP, from those with more complex HSP, from those who care for other, from ladies! It would also be great to hear from other minority characteristics – yes, we capture disability well and provide support to our members, but I don't know if our approach excludes certain sections of society that would benefit from our work. People do not have to have HSP to help the group, so please shout if you can help or you know someone who might be able to help.

Attending meetings

Briefly back to meetings, but this is about meetings where we've attended rather than those we've organised. Mike Cain has done the vast majority of the work here, having represented the group at over 80 meetings since the last AGM, including a trip to Westminster in February. Mike's work helps get HSP and our name into the wider rare disease and disability world, and this increased awareness is important.

Social Media

Here's a quick reminder of our four social media channels, facebook (+217), twitter(+50), linkedin (+8) and our new youtube channel (+104). The numbers in brackets are the increases in followers for each channel. Facebook and Twitter continue to grow at a steady rate, and we've had a great uptake on our youtube channel. LinkedIn is a bit more of a slow burner for now.

4. Secretary Report

Trustee Meetings:

Since the last AGM there have been five online meetings: 1st July 2020, 26th January 2021, 23rd February 2021, 8th May 2021 and 29th June 2021.

Old Charity number closed.

We registered the HSP Support Group with the Charity Commission as a CIO Association in accordance with the Constitution adopted at the 2018 AGM. This registration was accepted in January 2019.

In January 2021 we finally removed our previous registration from the Commissions web site – the two year interval was needed to complete full annual returns for each registration in turn.

Member Grants:

Over the year two grants to members have been approved.

Research grants:

We have paid one £15,000 instalment of a Grant for a PhD student at Exeter University.

We have also paid a Grant of £2000 to Sapienza University in Rome to support ongoing research into HSP linked neurodegeneration.

A third Grant is approved, but awaits payment due to delays caused by the pandemic.

Other Payments: A donation of £997 was made at the Potato Pants festival. We have agreed to assign that money to support a Members Grant – this helps us to give some positive feedback to those who supported the festival.

80 enquiries via Web Site:

As you will recall, we launched our upgraded web site a few weeks before the last AGM. The new site has generated a lot of interest, for example over the last year we have noticed an increase in the number of people contacting us via the site. As of mid May we'd had over 80 such contact messages in less than a year!

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

5. 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 AND EXPENDITURE ACCOUNT

Note: the report and accounts sent to Charity Commissioners in the format they require are on the website. These contain lines of information that are not relevant to HSP so I am presenting to members a simplified view of the accounts compatible with previous years' reports. The figures for total income, expenditure and funds carried forward are the same.

INCOME AND EXPENDITURE ACCOUNT FOR 2020-21			
INCOME	General Fund	Restricted Fund	Total Funds
Donations and legacies	6,774.42	459.42	7,233.84
Subscriptions	4,898.00		4,898.00
Fund Raising Activities	1,612.84	500.17	2,113.01
Local Fundraising			
AGM Lunches	0.00		
Total	13,285.26	959.59	14,244.85
EXPENDITURE	General Fund	Restricted Fund	Total Funds
Fund Raising expenses	102.84	18.08	120.92
Grants to Members	1,500.00		1,500.00
Local Grants from Fundraising			0.00
Research Grants		17,000.00	17,000.00
Newsletter	673.64		673.64
Regional meetings & AGM	110.84		110.84
Admin Costs	2,445.47		2,445.47
Expenses claimed by Trustees for attending meetings and Conferences	138.65		138.65
Total	4,971.44	17,018.08	21,989.52
Transfers between funds	15,196.20	-15,196.20	0.00
Net Movement in Funds	-6,882.38	-862.29	-7,744.67
Reconciliation of Funds			
Funds Carried forward from 2018-19	136,098.12	862.29	136,960.41
Total funds carried Forward	129,215.74	0.00	129,215.74

	BALANCE SHEET		
At 1 May 2020			At 30 April 2021
Current a/c	136,360.41		128,615.74
Prepayments	600.00		600.00
TOTAL	136,960.41		129,215.74
Allocated to Funds			
	2019-20		2019-20
General Fund	136,098.12		129,215.74
Research Fund (Restricted)	862.29		0.00
Total	136,960.41		129,215.74

2 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

6. Voting Results

This year, we tried and make our voting more accessible to members, allowing more of you to be able to vote on our business. Our current constitution allows for both postal and electronic voting, and we used those powers for this years vote.

Overall 77 members cast votes, which is about 20% of our membership. 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.

The proportion of postal and electronic votes roughly follows members communication methods, although there was a slightly higher turnout for electronic voters than postal voters.

A few members chose to abstain from one or two of the votes, but for the minutes, the accounts and the report I am pleased to report that these were all approved unanimously.

7. 2021 Awards:

When we were reviewing the nominations this year we couldn't decide between two of the nominations for fundraising, and so we took the novel step of having two fundraising awards for this year.

I remind you that any member is able to nominate anyone for either award. I would love to hear from more members about who has helped the group by raising funds or raising awareness. Those personal stories really do help make connections with people who haven't heard about it.

Raising Awareness Award.

Our raising awareness award this year goes to Jenni Preston, who has put in a load of hard work getting our new website up and running. Since we launched the website last year Jenni has been helping behind the scenes sorting out little issues that we've had and adding new pages here and there as things change, happy to work with the committees to develop various aspects. People should realise that the website works well on all types of device, which makes it easier for people to find out about us. I like that we're able to use the website to feed out news items and let the world become more aware of us and our activities.

As Dave mentioned the website has opened up a new channel of communication with people, and as Mitesh mentioned the website makes it easier for people to join the group, all thanks the Jenni's hard work.

Jenni has recorded a short video message of thanks

Fundraising Award

Our **first fundraising award** this year goes to **Estelle Marshall**.

Back before coronavirus was a thing Estelle Marshall had decided to climb Mount Snowdon, the highest mountain in Wales, and raise some money for the support group.

Estelle knew that climbing Snowdon was going to be a challenge with her HSP, but she was determined to demonstrate that she is still able to do some things. Along came coronavirus and its travel restrictions, meaning that it was impossible to go to Wales and do this. Estelle took inspiration from Captain Sir Tom Moore's 100 laps of his garden and decided to do 100 laps of her very steep garden to combine the climbing with the walking and using this to raise some money for the group.

Estelle's walk has raised over £700 for the group, and we are very pleased that she was able to find a way to support us in those most challenging times.

Estelle was quite surprised to find out that she has been recognised with this award, and she is here with us today, and with any luck the technology will let her say a few words.

Our **second fundraising award** this year goes to **Jade Bennett**.

Jade has been raising money for the group over a number of years by taking part in running events and getting sponsorship. Her first run for the group was the Bournemouth half marathon back in 2015, and since then she has taken part in two more half marathons and three full marathons, including running both the London Marathon and Edinburgh marathon within a month or two of each other in 2018.

For those of you who don't know Jades dad is Ian Bennett, our newsletter editor and former membership secretary and chair!

Back in 2015 Jade declared that she was not a natural athlete, and that first run was a huge personal challenge but she was keen to make a big difference to the group. Jade has indeed made a big difference, John told me the other day that Jades lifetime fundraising total for the group is not far off £5000, which is a fantastic total! Jades perceptions of herself as an athlete have also changed as she told me that she now runs half marathons for fun!

Jade is here with us today, and with any luck the technology will let her say a few words.

8. Trustee Election.

This year Mike Cain is the only trustee coming to the end of his three year term. Mike decided to stand for re-election, and you members voted.

As you can see Mike gets a clear majority and is re-elected as a trustee, and I look forward to working with him going forward.

There is more news on the trustee front. The trustees for this year, are Mike Cain, John Mason, Dave Harris and Mitesh Patel working with me. Everyone is carrying on in their roles with John being treasurer, Dave being secretary and Mitesh being membership secretary. I thank them all for their continuing excellent work with the group, and look forward to move the group forwards in a co-ordinated fashion. As I mentioned earlier John and Dave are looking to step down this time next year, which gives us a year to find people to take on these roles with a good handover.

You should also note that two trustees are standing down this year. We appointed Neil Cuthbertson as a trustee towards the end of 2020, but he has had some changes at work and felt unable to continue in the trustee role. Although Neils time a trustee was relatively short he made important contributions. Also Ian Bennett has decided to step down as a trustee at this AGM. As I mentioned earlier Ian has been working with the group for many years, and has been a trustee ever since our charity registration in 2004. Ian has collectively worn the greatest number of hats for the group, and members will be pleased to hear that Ian will carry on editing NewsLink. I asked Ian if he would like to say a few words to you, and using my best radio presenter voice I hand over to our studio down in Dorset.

Ian Bennett stepping down

Ian opened his stepping down remarks by noting that he had been active within the Group for nearly 20 years, and for most of that time he had been a Trustee. He recalled originally working with David Pearce, Mike Fawcett and Stephanie who were all instrumental in “getting the group going”.

More recently he was pleased to see the present strong team all working hard for the Group and taking it forward, Chairman Adam, Secretary Dave and Treasurer John all did a lot behind the scenes to help the group continue to thrive. He also thanked Mitesh who had taken over the reigns of Membership Secretary effortlessly.

His main reason for stepping down now was that he feels he has less energy and wants to do a bit less.

He intends to carry on with arranging meetings, editing Newslink and running Potato Pants festivals.

He wants to put out the next issue of Newslink before too long so asks members for their written contributions!

In closing he said he had been pleased to meet so many people over the years, many of whom he considered as friends for life. He looked forward to continuing his involvement in the future.

Group Name Change

Part of the reason for trying to reach out to as many of you as possible for voting was to capture a big as vote as possible for this important decision. 75 members cast a vote on this matter. Out of the four choices there were approximately the same number of votes for keeping our current name and for HSP UK. In fact, there was just one more vote for HSP UK than for keeping the current name.

We had a trustee meeting a few days ago to talk about this, and we decided that one vote was not sufficient large a majority to trigger a change in the groups name. So, we avoid making this vote like the Brexit vote, and we will carry on being the HSP support group.

I thank everyone that took the time to submit their votes in to us, and encourage the other members to use their membership to help us know how they feel about these important issues. I'm delighted that we've been able to allow any member to take part in this important group activity.

Out of the three name choices, it is clear that HSP UK is the preferred name, and we will explore if it may be possible to use this like a trading name in some circumstances.

For those of you who may be disappointed by our decision, we may review this issue again in the future, particularly if we are able to increase our income and have a stronger steer on types of research projects or have a greater influence in the rare disease community.

Lands End to John O'Groats

Firstly, I'd like to thank Rachel for this excellent idea. It draws on Estelle's approach of re-interpreting Sir Captain Tom Moores 100 laps of his garden. We would like the members of the group to be able to get, virtually, along all 1000 miles from Lands End to John O'Groats. Those who have been members for a while may remember that three people have actually gone from Lands End to John O'Groats to raise money for the group. Richard Williams cycled the route in 2005, and in 2016 it was done twice, by Simon Hubbard on his bike, and Stuart Montrose chose to walk it.

Members can use any method of transport they like, wheelchairs, mobility scooters, bikes, walking, swimming, and so on. I know there are members that like to ride horses and others that like to go about in boats – they would all count!

We'll work out the final details in the next few days, but we'd add together distances of everyone each week. If we took ten weeks to do this it would be about 100 miles per week, and if every member did 500 yards/meters per week we'd get this smashed easily.

Some of you will know that I ride my bike regularly, and so I will contribute about 60 miles a week to the total. We're also interested in capturing contributions of every scale – I was talking with my mum, who uses an electric chair all the time – she said that her Doctors is one mile up the road, so a trip for her to go to the Doctors would add two miles to the total. You can either log your normal everyday movements or you can set yourself a personal challenge. We'd be very happy to hear of all distances however big or small to work collectively as a team and move us forward together, from one end of the country to the other.

AGM 2022

This slide should look very familiar – I used it last year. **Next years AGM** will be on **Sat 2nd July 2022**. I really do hope that it is face to face back in the Tally Ho conference centre in Birmingham. Attendance will be free of charge.

Presentations – via Zoom

At the moment I've got three talks lined up for the summer. I'm trying to arrange one for the middle weekend of August so they are every two weeks going forward.

Saturday 17th July 15.00: We have **Henry Houlden**, who works at the National Hospital for Neurology and Neurosurgery in London, and has talked with us before. He will be talking about the range of HSP in the UK, with details of some findings from the 100,000 genomes project. He will also mention building a new registry, which is a new project idea we're starting to explore.

Saturday 31st July 14.00 At the end of July we have **Coralie Seary**, who is a physiotherapist working at UCL in London, and specialises in Functional Electrical Stimulation. She will be talking about falls prevention and management, looking at what might cause a fall, what you can do to manage your risk of falling, and what to do if you fall.

Saturday 28th August 15.00 At the end of August we have **Ray Owen**, who is the author of the book *Living with the Enemy*, as recommended at our 2017 AGM. Ray is a clinical psychologist, working in cancer and palliative care. He will be covering mindfulness, acceptance and values, talking about a recent, science-based approach to living well despite difficult circumstances.

We will follow the same format as last year, a presentation via Zoom with the opportunity to ask questions after. All three presenters have already agreed for me to put these presentations up on our YouTube channel. I hope to see many of you there!

Meeting Close

There being no further business the formal part of the AGM was closed at 11.15am.

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

13 July 2021