



# HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 56 – June 2024

HSP & FSP – Hereditary Spastic Paraplegia,  
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

## An Amazing Calvert Trust Experience



Calvert Trust holiday 11th to 15th September 2023 with Sue and Steve Foot, Terry Duffy, Lorraine Saupe and Brian Day

### Day 1

Lorraine and I planned our journey time for a pre-arranged meeting at McDonald's in Tiverton at 1 pm where we decided we would have lunch before moving onto Exmoor together. We arrived at exactly the same time as Sue and Steve. However, Terry's journey had been so good we discovered that he had been and gone from the restaurant and had driven onto Calvert Trust.

After lunch, we completed our journey to the holiday centre where we were welcomed by

the staff and shown to our accommodation. These were twin rooms with en-suite wet room and toilet. All were fully wheelchair accessible with fitted seats in the shower area. Baggage trolleys were available to take our suitcases from the car park to the rooms. There were slight slopes from the car park, but the ground was level around the accommodation block with a lift to the first floor. Our accommodation was ground level within a picturesque courtyard. After unpacking, we sat on garden seats outside our rooms when Steve discovered his

wheelchair had a flat tyre. After trying two electric pumps and using three patches from a repair kit, it was decided that the inner tube resembled Swiss cheese and was beyond repair. Fortunately, Steve had brought spare wheels. During this unscheduled pit stop, we made friends with a very tame Robin we named Woody. He would eat biscuit crumbs from our hands and would visit us throughout our stay.



Dinner was served each day at 6pm within the dining room for all guests.

There were 30 guests during our stay that allowed for comfortable seating.

Tea, coffee and juices were available 24/7 from the dining room and the meals were served from a counter where you needed to collect food yourself.

Carers were busy especially for wheelchair users at this time.

Dinner

Chicken pasta or Chilli con carni  
Chocolate brownie

After dinner, we all gathered within the bar room for an introduction meeting where we were advised about the centre's facilities, fire escape and other health and safety subjects.

We were placed into groups and shown our timetable of activities for the next three days. We met the rest of our team, Matt and Keri Ann, Joe and Farhan and Adam.

The bar was open from 7.30 to 11 pm each night. There was a pool table and football table available - free to play.

## Day 2

All members of the team woke up feeling a bit jaded, typical when sleeping in an unfamiliar bed and surroundings.

Breakfast

Choice of cooked meal or cereal.

## Crate Stacking

We assembly in a large hall where we were given a safety brief before given harnesses and helmets.

The task was working in pairs when we would be hoisted up by the instructors whilst we placed crates under our partner in turn thereby allowing us both to climb higher.

Other members of the group were required to pass by hand and then by winch the crates up to each pair as they made their ascent.

Working as a team and overcoming fear of heights was all part of the experience as was dealing with discomfort of pinching harnesses namely Terry's jaw, Brians stomach and Steves unmentionables.

All teams were thrilled and proud to reach the target of 18 crates before collapsing the crate tower beneath them and descending to the ground.



Lunch

Burger chips with salad

### **Horse riding / Horse carriage ride**

We were taken to the on-site stables where we were weighed to ensure we did not exceed the permitted weight to allow us participate. After passing the test, we were given a riding helmet.

We met the horses all of which were friendly and well kept within clean stables. Each stable was fitted with a plaque providing the horses name along with a brief description giving their history and personalities.

Each member of the group was given the opportunity to ride or be carriage driven around a small section of the centre to an outdoor arena to complete a figure of 8 driving course.

Whilst you were taken on your individual ride, the others in the group were given opportunity to either groom the remaining horses or muck out. To be honest, grooming was more popular.

Due to the restricted bar opening time, Lorraine and I took a short drive to the nearby village of Combe Martin for extra supplies of beer, wine, chocolate and crisps. These necessary comfort items allowed us to relax outside our rooms for a pre dinner wind down reflecting on the days events. This unscheduled event was gradually extended to invite all of the team by the end of the week.



Dinner

Beef hot pot  
Chicken curry  
Ice cream

It is possible to decline any activity if you don't wish to participate. The centre had organised an arts and craft session for all guests. We decided to miss this event and instead located the conservatory to relax. This room had a balcony which provided a beautiful view overlooking the lake.

### **Day 3**

A better nights sleep.

Breakfast

### **Archery**

Ready for competitive session especially as Terry already regularly attends an archery group. After an instruction and safety talk and a few practice rounds, games involving the target scores were introduced.

Snakes and ladders was the best game where a close match was won by a winning shot from a thrilled and equally surprised Lorraine.

Everyone from our group enjoyed Archery. It is sport that is open to anyone and allows fair competitive involvement.

The bows were basic design and not too heavy to pull. For those with arm weakness, a bow was mounted on a specially designed frame for aiming and could be fired by a gentle pull on a string.

The instructor told us a previous guest who was paralysed was able to release their arrows using a string attached to their helmet and a gentle rock back of their head.

Lunch

Jacket potato

Note: The centre will provide alternative lunches and dinners such as sandwiches upon request if advised before 10am each day.

### **Canoeing**

Some trepidation within our group prior to this activity regarding getting in and out of the boats, falling in, etc but we needn't have worried. Safety talk and life jackets provided.

The staff were helpful and considerate to assist us with dignity as we climbed into the

boats. The boats were two canoes joined in two places with lengths of wood making them very stable in the water whilst helping as places to hold as we got in and out. The seats had backs and were raised to allow you to bend your legs. No straight legs as I feared.

The deck of the canoes were dry as a bone which was comforting too.



A quick instruction on using paddles followed by a turning game to face points of the compass before our two teams of 5 paddled across a still lake to play two games.

The first game was to collect the most plastic ducks thrown by the instructor to multiple directions and distances. Water was starting to enter the boats at this stage, but it was due to us using the paddles to scoop out the ducks.

The second game was battleships where the object was to throw a ball into the opponents boat without it bouncing out. This task was complicated further as the ball had to be passed to each team member before the ball could be thrown.

This was my favourite event where the competition was intense requiring co-ordination and teamwork, but the howls of laughter along with the best weather of the week brought our group so close. All that followed in the remaining days was joyous.

The journey back up the hill from the lake was steep in parts where loose stones changed to a zig zag concrete path. It would have been a struggle in my manual wheelchair compared to the motorised chairs and scooter used by Terry, Steve and Lorraine. Therefore, a big thank you to Keri Ann who pushed me back.

Dinner

Beef hot pot

Pasta Bolognese

Sticky toffee pudding

The evening entertainment began with a quiz based on Calvert Trust history and location.



The rest of the evening involved me discovering Exmoor Gold beer and group singing Karaoke.



**Day 4**

Waking with a slight hangover.

Breakfast

**Abseiling and Zip Wire**

Safety instructions and harnesses issued before going outside to the artificial rock face. The weather had changed and it was chilly waiting for each others turn.

I am not sure if it was that I was feeling cold and I wanted to exercise harder or I was still drunk from the night before. Either way, I decided to walk rather than abseil in a wheelchair.

I fell to the side three times during my decent, but I always felt safe. I loved the experience and was proud to complete something I always wanted do. A good opportunity to have a lie down halfway and have a chat with friends I thought.

The others were really impressive and all managed to achieve their goals without drama.

The zip wire was less eventful although quite exciting flying 20 feet over Sue's head as she filmed each of our journeys.

Lunch

Sausage roll and potato wedges

**Forest Craft**

Our group split for this event where you were taught about wildlife and learnt how to make fire and toast marshmallows. Sue, Steve and I went swimming whilst Lorraine and Terry spent the afternoon with Woody the robin.

The full team gathered outside our rooms for our final unofficial pre dinner party. Carers, Keri Ann and Farhan, taking an opportunity to drive Terrys powered wheelchair around the courtyard.

Dinner

Cottage pie

Chicken Kiev

Banoffee pie

The hosts provided a final night disco which allowed a great opportunity to let our hair down. Many requests for cheesy tunes and party dances. The disco finished at 10pm so the hardcore amongst us requested the

karaoke which kept us amused a while longer until good night campers.

**Day 5**

Feeling sad whilst packing before breakfast. We needed to leave our rooms by 10 am.

Final breakfast where we arranged to meet outside reception for a group photo and exchange contact details. Our group had bonded so well and I am sure we will remain friends staying in contact for a long time.

Returned the room keys to reception and thanked the staff for everything they had done. Packed the car before saying goodbye and making our separate ways home.

Lorraine and I spent our three-hour journey home without the radio, just talking, laughing and recalling moments from the last five days.

Thank you, Calvert Trust, all staff, all guests especially our brilliant team and to the late David Pearce of the HSP support group who generously provided a grant allowing us to have one of the best weeks of our lives.

Love and best regards from Devon.

**Brian Day**

## Editor's Column

I began my column in the last edition apologising for the long delay and unfortunately, the same applies on this occasion. This is actually a special edition of the newsletter, it's the 56<sup>th</sup> one I've produced in this format, and I was involved in a fair few prior to this, over a period of time in excess of 20 years. Regrettably, this will be my final one and this issue is only being transmitted by email. My main reason for this is that I simply find it too much because I currently have loads going on in my life, most of which is great fun, but also time consuming and energy draining. I've also found that since I've not been our Membership Secretary, I've had less contact with members and consequently, I've been finding it harder to consistently get interesting material for the newsletter. I hope someone comes forward to take it over and of course, if I can be of any help with this process, I'll be more than happy to assist.

I'd like to thank everybody who's helped me with the newsletter since I've been compiling it, whether that's by providing such interesting material for inclusion, or proofreading it to help eliminate all my grammatical errors, almost making me appear literate.

I still enjoy hosting a weekly radio show for a local radio station and I know some readers have listened in. If you ask Alexa or your smart speaker to 'play Forest FM' on a Friday evening at 8pm, you'll be able to have a listen, but don't expect to hear anything familiar because I only feature local musicians. If you let me know you're tuning in, I'll do a dedication for you. It's surprising how much preparation goes in to producing a one hour radio show.

I mentioned my new hobby of wheelchair racing in the previous edition. Since then I've entered some races and I haven't come last in all of them. It doesn't happen very often, but believe me, it's very satisfying overtaking competitors who are in their teens. This activity is all about technique and I'm still improving on a weekly basis and have now completed half marathon distance in under two hours. I'm hoping to enter two half marathons this year, including one in Guernsey in September.



I continue to enjoy hosting the monthly Zoom meetings, particularly so when we encounter new HSP'rs who learn so much from chatting to everyone in attendance. Next year, I may change the day of the week that these take place, simply because I have wheelchair training on a Wednesday evening, and as you've probably guessed, I'm really enjoying this activity.

My three grandchildren continue to keep me busy with regular babysitting duties, but they've become my three best friends and are the highlight of my life.

I'd like to tell you about a discovery I've made that is beneficial to those who use a wheelchair. This will also make our young, techy readers giggle because it's only because I'm old and out of date, that this has taken me so long to realise. I've always found it very hard to answer a mobile phone when using my wheelchair. I often found that by the time I'd pulled it out of my almost inaccessible pocket, I'd either hung up accidentally or missed the call. For this reason, a couple of years ago, I bought a smart watch, which communicates with the phone, enabling calls to be answered on the watch. However, in the winter, this isn't ideal because the watch can be covered by several layers of clothing. I've now found the solution! This old grandad has finally discovered ear buds and they're amazing. I have a pair of Sony ear buds and they connect with the phone by Bluetooth. I now enjoy listening to music while out and about and calls can be answered with the touch of a button which is located in the centre of the bud. Pressing the button again terminates the call. I'm astonished at the call quality, and I now don't venture out on my wheelchair without using them. I use fingerless wheelchair gloves to ensure that the ear buds are completely accessible. I suspect that you get what you pay for, my Sony ear buds were about £60 from John Lewis but I notice you can pay well in excess of £200 for different makes and models.

Towards the end of last year, together with my family I enjoyed a 5-night cruise which took us from Southampton to Rotterdam and Cork. This was my second cruise, our first was with Royal Caribbean and this was with MSC. On both occasions I've found the ships to be 100% accessible for wheelchair users and for this reason, this will now be my preferred method of holidaying. Next year I'm planning a 14-day cruise to celebrate a family birthday and it's looking like it may be a trip around the Mediterranean.

Thank you so much for reading my newsletters over the past 20 years. I've

enjoyed compiling them and always tried to keep them a little upbeat. I feel there's far too much negativity in our lives and I've always tried to keep this out of the newsletter. There are so many people I could thank for helping me with the newsletter but one particularly stands out. Special thanks to John Mason for being such a thorough and efficient proofreader and consequently improving the quality of the narrative.

**Ian Bennett**

## Chairman's Column

Hello to all our members and others reading, I hope that you are well. I'm writing this column during the May school half term, having just moved house. My life has been fairly hectic over the last few months, and I apologise for not being able to give the support group the time and energy that it needs over this time.

### We need help!

It feels like we're getting to a crunch time with the group. There are three key areas where we need help, and I'd be pleased to talk to anyone about help they can give, please e-mail me at [chair@hspgroup.org](mailto:chair@hspgroup.org)

Secretary – People who have been members of the group for a few years will note that Dave indicated his wish to stand down from the group secretary role. We need an individual who is prepared to be the secretary for the group. This involves dealing with correspondence with the group from members and researchers, dealing with the Charities Commission and with the group's memberships. There are details of what is expected on our website:

<https://hspgroup.org/want-to-be-able-to-help-the-group/>, and we would be happy to talk to two people who wished to share this role.

As you will have read in Ian's column, this is his last NewsLink as editor, and we also need an individual who would be willing to take on this role. This involves seeking out stories from members and other relevant people and presenting them in a readable format for us to distribute to members. In an ideal world we'd

have 2-3 issues per year, but we can talk with anyone who is interested in giving this a go.

Lastly, there is a general call out for people who would be able to organise meetings for the group. There are parts of the country where we have members, but no meetings. There is an excellent meeting organisers pack which gives lots of ideas and information. We're happy to hear from people who are interested in giving this a go, even if it is for a trial meeting in their area.

Dave and Ian have been key people within the group, helping it move forwards, and I thank them for their time, enthusiasm and commitment to the group. As time passes we need to get new people running the different aspects of the group, so that we have fresh ideas and new enthusiasm. New voices keep conversations current and activities fresh. As a small charity we rely on people volunteering their time. We need people who are willing to have a go organising, and be proactive keeping themselves on track with tasks. If you're interested, then drop me a line to talk. People do not have to have HSP to be able to help us, they just need to be willing to be active.

### AGM

With my hectic few months, I've not had a chance to think about our AGM yet, or the presentations which follow. After discussions at our most recent trustee meeting we agreed the AGM will be on Saturday 24<sup>th</sup> August. This will be a virtual AGM using Zoom and we will share more details once they become available.

### My HSP survey

As many know, I run an annual survey on my HSP blog. Circumstances meant that you were not able to read about my 2022 survey in an earlier issue, and I don't think there is room in this issue for you to read more than the headlines from my 2024 results, a compilation of key results from the ten previous surveys. Below are summaries of both surveys, with links to further reporting on my blog.

#### 2022 survey, reported February 2023.

<https://hspjourney.blogspot.com/2023/02/2022-survey-results.html>

513 respondents completed the on-line survey. Around 80% consider themselves disabled. Mobility is often the main factor determining if someone feels disabled. Walking sticks/canes were identified most often as people's favourite mobility aids amongst a wide range. Those who have negative feelings about using mobility aids tend to have a lower wellbeing. Benefits from mobility aids include increasing independence, reducing symptoms and enjoying doing more. Many have uncertainty about the types of mobility aid they will need to use in the future.

Around three quarters say they get pain from their HSP. The most common description of pain from HSP is 'tiring or exhausting'. Most people note their pain from HSP is in their legs, feet, back and hips.

People were asked how common HSP symptoms varied during their menstrual cycle. Over half felt their mental health was worse during their menstrual cycle, and around a third thought their spasticity, pain and/or fatigue were worse during their menstrual cycle. For a few with earlier onset HSP there are some reasons why people avoid using tampons.

People identified one piece of advice for others with HSP. The most common answers were around staying positive and keeping moving. There are many with HSP who find making or keeping friends hard, which leads to a lower wellbeing. Similarly, people can have lower wellbeing when they find it hard to tell their friends or work colleagues about their HSP.

### **Summary of ten surveys, reported February 2024.**

<https://hspjourney.blogspot.com/2024/02/2023-survey-highlights-of-10-years-of.html>

There have been 1,740 people completing at least one survey with 2,784 responses in total across 10 surveys. The advice suggested for others with HSP is around staying positive and keeping moving.

The HSP symptoms with the highest impacts on wellbeing are: pain, bladder, co-ordination and learning/memory. Symptoms that are

major for more than 50% of people are: difficulty running, difficulty walking, difficulty using stairs, muscles stiffness, loss of balance, getting more stiff when it is cold, and muscle weakness. Fatigue is the symptom which has the greatest effect for the greatest number of respondents. Difficulty walking and loss of balance were 2nd and 3rd.

Factors affecting walking the most are: where stairs/steps are involved, tiredness/fatigue, going over uneven ground and carrying something. Over 90% have problems with balance, tripping up and/or falling.

Around 85% are prescribed at least one medication for their HSP. There are more people taking medicine for spasticity or spasms than for other reasons. Baclofen is the most common medication for HSP with around half of people taking it, accounting for around one third of all medication.

Stretches are the most common exercise with over 75% doing this regularly. Other activities commonly undertaken include walking/running, physiotherapy, music and cycling/manual wheelchair. Six modifications at home are mentioned by at least ten respondents: grab rails, ramps, accessible/raised toilet, stair lift, bath seat/shower seat/bath board, convert bathroom to wetroom.

Around one quarter of people should be assessed for depression. More than 80% of people have bladder issues. The biggest bladder issue for wellbeing is having to rush to the toilet. Most people (59%) use at least one bladder control method. Results show most (62%) have moderate fatigue.

**Adam Lawrence**

## **A Big Thank You.**

As many of you will be aware I have been doing research on HSP and have had a brilliant response with over 100 people completing the questionnaire and conducting 9 interviews. I am very grateful to everyone who has been involved and I want to give feedback on some of the findings, although I am going to do a more comprehensive feedback session on Zoom. I have enjoyed



doing the research and found it interesting, I think having HSP myself makes it feel so important and relevant to me.



The first thing that came out of it was that I was not on my own in finding the diagnosis process and receiving the diagnosis traumatic. Relief was common around receiving the diagnosis, for some this was due to the fight that they had had to get a diagnosis and for others it was relief that it wasn't anything worse. Many people expressed fear and worry about the future for themselves and their children. Feelings around grieving were expressed by many with shock, depression, loss and sadness. This highlighted the need for emotional support for people going through this.

The information provided at diagnosis was variable, 55% were provided with an explanation of what HSP is but 24% were given no information. Most people reported doing their own research after diagnosis and the support group was mentioned by many as a place to get information and support. The benefits of connecting with others with HSP were expressed by many and it's a shame that few people, 21%, were provided with information on the support group at diagnosis.

Most people had awareness of the importance of physiotherapy, but the experience people had was very variable. The

physiotherapy treatment that has been the most useful to people has been stretches and then advice/provision of walking aids. Frequently people accessed physiotherapy privately.

Exercise is very important with long-term symptom management and the importance was recognized by most people with HSP. Stretches were by far the exercise that most people got benefit from. How people felt about exercise impacted motivation and many people had found exercise that they enjoyed.

**Estelle Marshall**

## Trains, Boats and Planes

Attending Ian Bennett's monthly zoom session, and having read in Newslink 55 Jacqueline McLaughlin's excellent article about buying a powerchair, I thought that an article about the ins and outs of travelling substantial distances with a powered wheelchair might be helpful.

I have a small folding wheelchair, a Mobility Plus Ultralight Instafold, which looks very similar to Jacqueline's machine. It weighs 26 kilos and folds to the size of a medium suitcase. It was bought on the strict understanding that it was fully compatible with airline requirements, because we travel a lot abroad as well as in the UK. How far has it met our needs and how co-operative have we found transport authorities?

### Trains

I have to start out with a warning that with UK rail provision split into different companies our experiences might not be identical with people in other parts of the country. We live 30 miles north of London so we mostly deal with Great Northern and occasionally Thameslink. We have found both to be excellent. It's imperative that you ring their dedicated "assistance" line in advance and are explicit about what you need (ramps to get into the carriage? Anything else?), and the time of the train you mean to catch. Book the return journey at the same time to give the whole picture. Also, where possible choose to travel from and to a station which is

continuously manned, problems can arise if it's a station only manned at peak hours! We normally use Hatfield, not the closest to us but always staffed. We have done probably scores of trips into London. The only time there has been any trouble was on returning from London the message that we needed to be met with the ramps didn't get through to Hatfield and there was a hideous scramble to get off on arrival which was only managed because other passengers helped lift the wheelchair off the train!

Another good thing is that the railway staff are flexible and accommodating. Sometimes it happens that we want to return from London earlier or later than the booked time. They have adjusted easily. Probably it helps that we are relatively regular customers, we always express our appreciation of their efforts and actually have quite a friendly relationship with many of our railway staff helpers.

We also took the wheelchair to Amsterdam on Eurostar and that worked really smoothly as well.

### **Boats**

We have never done an ocean cruise though I remember Ian Bennett saying he had and it went well. He might be the go-to man on that subject. We have taken the wheelchair on the Hurtigruten (a cruise up the coast of Norway from Bergen to the Arctic Circle ) and on a cruise on the Rhone river in France. The wheelchair's predecessor, a foldable electric scooter of roughly the same dimensions, went on a cruise on the Mainz in Germany. In each case much the same happened. We gave full information about the specifications which the tour operator accepted. However they warned us that we (Anne and I) would be responsible for getting the vehicle on and off the boat when moored at places of interest and that might be difficult if, for example, our boat was on the outside of a "double parking" and we had to cross another boat to get to shore. However, in each case the boat's crew were highly co-operative. On one of the trips Anne expressed concern and the captain said "I have big boys" and sure enough a big boy crew member tucked the folded wheelchair under his arm and leaped off the boat to

shore! So no problems, but you can't rely on such support; we had taken a risk. We would take the risk again, but someday it will go wrong and we will have to stay on the boat when others get off to sightsee.

### **Planes**

One of the few places I feel my disability is an advantage is at the airport. I get treated like royalty. Again, it's imperative to provide full information about the wheelchair to the airline you are flying with and to demonstrate it comes within their parameters for weight, size, battery power etc. Once that's done, it's a doddle. On the day you identify yourself at the assistance point at the airport and you immediately soar through all queues at baggage check etc. Coming home from abroad is even better, you avoid all queues at passport control etc. On the journey the wheelchair goes into the baggage with golf equipment, children's buggies etc though normally you have to detach the lithium ion batteries and take them with you into the seating area of the plane.

Things can go wrong of course. Once, returning from abroad to Stansted, we found the wheelchair had somehow been sent to Hamburg. It was returned to us in a couple of days. And once, when the wheelchair was put into the luggage with the battery attached, the runner for attaching the battery to the wheelchair was partly broken. But over quite a few years of air travel with a powered wheelchair, the experience has been overwhelmingly positive.

### **Conclusions**

First conclusion, go for it! Careful planning and advance preparation are essential, so more effort is required, but if you put in the spadework most obstacles can be overcome. Second conclusion, in planning a trip by train or boat or plane read the instructions from the travel provider and follow them to the letter. If in doubt, consult their customer services. Third, have faith in your fellow man (and woman). In all our travelling the norm has been constructive helpful behaviour from airport and airline staff here and abroad, from rail and cruise staff also. Happy travelling!

**Mike Horsman**

## Amazing opportunities available with The Calvert Trust

Some of you may remember our former Chairman David Pearce. On the front of the August 2006 newsletter David wrote an article about how much he enjoyed a stay with the Calvert Trust. You'll have also read the headline article of this edition, covering five of our members who've recently had an amazing experience with the Calvert Trust on Exmoor.

For those of you who don't know, the Calvert Trust is an organisation with three locations around the UK, where they provide many exciting challenges for disabled people. These challenges include horse riding, kayaking, sailing, archery, cycling and abseiling to name but a few. I can remember David telling me what an incredible experience this was and he'd be delighted to know that some of our members have recently discovered for themselves how much fun and uplifting a Calvert Trust break can be.

Sadly, David Pearce passed away in 2018 but he very generously left us some money in his will. Some of this was used for research but we wanted to use some for a purpose that we knew David would fully approve of. For this reason, we decided to pay half the cost of a Calvert Trust experience for any member. This is limited to one holiday per member every two years. We have allocated a certain amount of money for this and when it's gone, it's gone.

Please check out the Calvert Trust's website and if you like what you see, get yourself booked in. The HSP Group will refund half the cost.

For more information on this contact a trustee.

## Fundraising News

### Thanks to all who have raised funds for us using Easyfundraising.

If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. Use the following link and follow instructions:

<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/>

**We are also registered with Amazon Smile so you can now raise funds for the group when shopping at Amazon.** To use this go to:

<https://smile.amazon.co.uk/ch/1181539-0>

and that will help you select the group as your charity. The difference from normal Amazon shopping is that you need to remember to do your shopping from

<https://smile.amazon.co.uk/> so that the donations come through.

Covid meant that we all stayed indoors for far too long. It is time to get out there again and think of ways to get some exercise and in doing so, maybe raise some funds for HSP. If you are running in an event for HSP, we will be very happy to provide you with an HSP Support Group running vest.

**Ian Bennett**

## HSP Group Grants

**Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier.**

The maximum grant available is currently £1000. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from the Secretary Dave Harris, details at the end of this newsletter. There is also an online form available via our website.

## Zoom Meetings for all HSP'rs First Wednesday of every month

These meetings began during lockdown because we felt that it was important to give people the opportunity to get together and keep in touch with one another.

I volunteered to host them and have really enjoyed doing so. Attendances vary from about a dozen people to 40 and these people are always spread all around the UK. Since lockdown attendances have understandably

dropped a little but a wealth of information has been shared. The list of topics discussed is far too long to print, but mobility aids, disability benefits, exercises, holidays, different types of HSP, symptoms, HSP specialist locations and medication are regularly discussed.

New friendships have also developed which are always a highlight for me and on a few occasions, we've had people attend who have never come across anyone else with HSP.

These meetings begin at 7pm and usually end at around 9pm but people are free to come and go as they want. We have people who love to talk, and we have others who love to listen and learn. Both types are very welcome at these meetings.

Invitations and reminders are sent out to members by email.

I look forward to seeing regulars and new faces at future meetings. If you'd like further information on these meetings you can contact me by email

[bravoechoonovember@btinternet.com](mailto:bravoechoonovember@btinternet.com)

**Ian Bennett**

## **Feering, Colchester Branch Meeting**

We met at Feering Community Centre, near Colchester in Essex on Sunday, 22nd October 2023.

We met over tea and coffee, catching up on news and sharing information. We talked about wheelchairs and the availability of Wheelchair Services while commiserating with the member whose wheels keep falling off and rolling away out of reach... Some members discovered shared interests that can be pursued online – one positive to come out of the covid pandemic.

Our next meeting is on Sunday, 21st April 2024 from 2.30 pm - 5 pm. It will be at Feering Community Centre, near Colchester, Essex, CO5 9QB. As always, everyone is very welcome to join us. Any questions, just get in touch with me.

**Hilary Croydon**

## **Burnley Meeting Sat 21<sup>st</sup> October 2023**

Attended by 3 members with HSP, and 2 came with a family member.

We started with a general chat getting to know each other.

I did a talk on physiotherapy and spoke about the limitations in service provision and the importance of self-management.

We looked at exercises that are of benefit, breaking it down into 3 groups.

Stretches- These can be done in different positions, sitting, standing, and lying.

Balance- Has to challenge balance (feel unsteady) but done safely.

Cardiovascular- Raising heart rate

Then, I looked at Fatigue management the importance of listening to your body, and how fatigue differs from being tired.

The benefits of weight-bearing for those not able to walk.

I pointed people toward the talk on walking aids that is on the HSP support group U-tube channel.

I finished by talking about exercise being individual building into a routine and finding exercise that is fun.

I aim to do some more work on this presentation with a view to doing on Zoom.

**Estelle Marshall**

## **Milford Afternoon Tea- November 2023**

Whilst the Carers were having their time together, the rest of us were catching up and enjoying a chat. As our guest speaker for the meeting, we were very pleased to welcome Professor Sue Lanham-New, who is a Registered Public Health Nutritionist, from the University of Surrey. During the pandemic, having a nutritionist as a speaker was suggested. Sue joined us early, so she had time to meet everyone. Good nutrition is key to keeping us well and maintaining the strength we need to keep mobile, in whatever form we use. Rather than talk about diets, Sue focused and explained how we can maintain our body strength and health. One key nutrient discussed was Vitamin D, especially

as we often have limited sunlight in the UK. Following the meeting, members have started taking Vitamin D which is needed to keep our muscles and teeth healthy. I've been asked by several people to ask Sue back again. 'Watch this space' as people say!!

We fully understand that travelling to face-to-face meetings can be difficult and not always possible. Consequently, we are always pleased to see everyone who can travel to Milford, and appreciate that for those that can't travel, the monthly Zoom meetings are beneficial. We were very pleased to welcome a new member who had travelled from S.E. London to Surrey for the meeting.

Phil Bungay and his wife joined us from the Medway Towns, and were able to explain and promote the Medway Neuro-Cafes, which he has pioneered. For those living in South East London and Kent, the Medway Neuro-Cafes offer a more local place to meet others with similar difficulties from neurological conditions whilst enjoying refreshment and having a chat. If anyone is interested, here is the link.

<http://medwayneuro.org.uk/medway-neuro-cafes>

Our next Afternoon Tea is Saturday April 6<sup>th</sup> from 3pm until 6pm, at The Clockhouse. We look forward to seeing you there.

### **Milford April Meeting**

Following the Carer's time together, we were pleased to welcome Tel Martin from AGEUK as guest speaker. Tel's topic was 'Planning for The Future', which is being pioneered in Surrey, covering all the aspects of life we need to consider, regardless of our age. These include making a will, organising your Lasting Power of Attorney, and with our disability in mind, paying for our future care. A number of these factors depend on families communicating, which isn't always easy. Tel gave the example that in a family where the siblings didn't get on, the parents filed all the relevant documents and then brought everyone together and explained their system in the event of their death.

The 'Planning for The Future' document included a number of useful Surrey links, but

knowing that people travelled from other areas to Milford, Tel kindly prepared supplements for the areas where people lived.

We are very lucky that so many regularly travel to the meeting in Milford, but are delighted, as we were, to welcome new members and their families. The combination of established and new coming together, has created the benefits of sharing. For example, so often new people will ask about walking aids and equipment and with the wealth of knowledge of others, there can be a lot of discussion and often showing of items to answer the questions.

As many have to travel a distance to Milford and driving home in the dark can be difficult, we are holding our autumn meeting a month earlier, in October. We're looking forward to seeing you again on Sunday 6<sup>th</sup> from 2pm until 5pm.

Hoping you have an enjoyable summer.

Best wishes,

**Michael and Jane**

### **Birmingham Get-together – Saturday April 13th 2024**

A bright sunny day brought 25 lovely folks to the Birmingham get-together. We had 14 regulars. 3 couldn't make it due to illness, and 11 newcomers!! - 6 of whom have HSP. Incredibly 5 of them hadn't yet met anyone else with HSP and were really delighted to be able to join a face to face gathering. One of our newcomers came with a beautiful Assistance Dog called Annie, who absolutely loved the attention of everyone and was very relaxed and calm throughout the afternoon. She was and always will be very welcome – not something that can be experienced/achieved on any zoom meeting!!

Straight away folks were engaging in conversation and we didn't really want to break the party to have to do all the 'admin' bits. We gave everyone a lovely warm welcome and asked if people would be happy to join an HSP Birmingham WhatsApp group. A piece of paper was offered for anyone to write down their email addresses and mobile

numbers if they wanted to be included. Absolutely everyone was very happy to do this, Penny kindly set the WhatsApp group up over the weekend, and they have been communicating already!!

We asked the group if there was anything specific that they would like us to try to arrange for our Autumn gathering and we hope they will be using the WhatsApp to let us know.

So many of our newcomers told us how little information/help was given to them by their medical professionals and were desperate to see and talk to others to find out how we were all affected by HSP. They wanted to see how we walked, what devices were used, to be able to ask questions, and to chat and compare their own journey. Some hadn't seen Flexyfoot sticks/feet and asked to try ours out – all of which can only happen at a face to face get-together.

Many asked about the next AGM, and whether it would be a face-to-face this year, but were very disappointed to find out it was by Zoom again.

We shared a buffet lunch together and the general feedback of the whole day was extremely positive. Two newcomers have already arranged to meet.

We are looking to have our Autumn get-together in mid – October. Please look for details on the website, Facebook or in the next members' Newslink.

From Penny Cohen & June Masding (Co-ordinators for the Birmingham Group)

## Forthcoming Events

### A Zoom meeting for all members

#### Simply a natter to catch up with old friends and maybe make some new ones

The first Wednesday of every month 7pm, online using Zoom.

Zoom details are emailed to all members or Contact Ian Bennett: 01202 849 391 or [bravoechoonovember@btinternet.com](mailto:bravoechoonovember@btinternet.com) for info

## Potato Pants Festival 2024

You'll notice by the poster below that the festival is a little different this year. The main changes are that it's indoors and it's in October. There will be bands supporting.



For ticket information or further information contact Ian Bennett.

## Birmingham/West Midlands

October 12<sup>th</sup> 12.00pm – 3.30pm  
at The Kenrick Centre, Mill Farm Road,  
Harborne, Birmingham, B27 0QX  
[pennycohen57@hotmail.com](mailto:pennycohen57@hotmail.com) or  
[june\\_masding@hotmail.co.uk](mailto:june_masding@hotmail.co.uk) for details

## Colchester/Essex

Date to be confirmed  
Feering Community Centre  
Contact Hilary Croydon for further  
information Tel: 01284 728 242  
[tohiti@btinternet.com](mailto:tohiti@btinternet.com)

## Milford

Sunday October 6<sup>th</sup> 2pm – 5pm  
The Clockhouse Milford  
GU8 5EZ  
Call Jane Bennett on: 07763 490 251

## Useful Contacts

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