

HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 47 – September 2019

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

Isle of Wight race.....without a boat



Andy's 11 yr old grandson

In Feb 2019, like most people, I'd never heard of HSP before. That changed in March, when my grandson was diagnosed with this condition. He's 11 now, and has never been able to walk. And, despite an operation and countless tests, his condition had never been diagnosed, until

now. That was when some genetic tests finally revealed the cause.

He has what was described as the most severe form. I didn't know what this meant so, as one does these days, I went online and became an instant internet "expert" on the subject! During this research I came across the HSP Support Group, and decided there and then to try to do some small thing to help them with their funding of research into HSP and their support for affected families.

A passion for events

I compete in ultra foot-races (an ultra is anything longer than a marathon), and each year I do an event to raise money for a good cause, selecting a different one each year. Every year, without fail, the choice of charity presents itself to me in some way, and this year turned out to be no exception.

As I'd never been to the Isle of Wight before, I decided to take on the coastal-path challenge, a 66-mile non-stop race around the island! It starts early on a Saturday morning, and whilst you have until 6pm on the Sunday afternoon to complete it, my goal was to finish before midnight.

You desperately hope for dry weather on these things, as wet feet over long distances can change everything (i.e. it hurts!). Mercifully the weather was on my side, although it was touch-and-go for a while there, when during the night the starting-point campsite at Chale got lashed by an unexpected storm. The rain continued almost up to the start-time but, at the last minute, it thankfully stopped.

The adventure begins

So, at 6:45am on Sat 4th May, a chilly crowd of 586 of us set off to begin this adventure. We were heading clockwise from Chale, which is near the southernmost point of the Isle of Wight, we first went NW alongside the Military Road (originally built as part of some 19th century island-defences), which afforded us spectacular views of The Needles in the distance.



We had a brisk side-wind for company (I guess the weather-Gods decided that if we weren't going to get wet, then we were going to get cold and blown instead!), and meandered along the clifftop path. In modern Britain it's quite surprising that you're still allowed to have a path so very close to a cliff-edge. At points the path was barely 4 feet wide, with barbed wire on one side, and a gusting wind blowing you towards the sheer unguarded drop on the other side! I appreciate that 4' isn't exactly death-defying, but you're nonetheless very aware that you don't want to trip and risk taking a tumble towards the edge!

At 10km in, we reached the first checkpoint (CP1). This is a charity event, so they tend to try to make the checkpoints different to each other and also deliberately memorably-themed – for instance, one was a pick'n'mix stall, and another was a pizza place. This first checkpoint was a pastry “shop”! You can eat as much as you like

at each of them, but I've done enough of these events to know that – whilst visually appealing – these sort of things aren't really what you want to (or rather, should) be eating. I therefore stuck to simpler fare on the way round... cereal bars, bananas, and jelly-babies. Not really the most thrilling of diets, but the best plan if you want to get to the end. After all, you can always stuff your face once you've finished!

We turned across The Needles and descended into CP2, with views across the Solent of the mainland (or “North Island”, as some IOW residents call it!), then headed NE towards Cowes. A scenic, sometimes-wooded section into the headwind saw us into CP3, after which the coastal-path went for the first of its several deviations away from the coast, on this occasion around some MOD land on the coast, and along some fairly quiet country lanes.

Halfway round

7 hours later, and 33 miles in, I arrived at the halfway point in Cowes. I knew that we'd have to catch the chain-ferry across the River Medina that was 1km away after the checkpoint, so while some people chose to stop there for lunch (several of the checkpoints offer full hot-meal stops, including this one), I chose to push on.

Actually, I tend not to hang around at any of the checkpoints, through fear of seizing up. So, I just grabbed some cereal-bars and jogged on towards the ferry, just in time to see it arrive the other side! Oh well, luck of the draw! I wasted 20 seemingly-interminable minutes there before getting across, then continued onwards, along another lengthy inland road-section. This time, however, it was a busy main road with no pavement. A bit risky for 500+ of us on the full-island route, not to mention the hundreds of others competing in some of the other shorter-distance races available, but I can only assume that the organisers had no choice.

Thankfully that passed without incident, and the path re-joined the coast at Ryde, where CP5 was ready to shovel food into us! I left there after the usual brief stop, enjoying the expansive views across to Portsmouth harbour and the impressive-looking Spinnaker Tower there.

Racing the sunset

Throughout the event, I was mindful of a rule the organisers have, that you're not allowed to leave a CP on your own if it's dark, as they don't want people being on their own at night.

As I was competing on my own, and trying to set a good time, I really didn't want to have to (and wasn't sure that I'd be willing to!) wait for a group to form at a dark checkpoint before being allowed to leave, all the while watching the time ticking away. I knew that by then the field would be well spread out, and it could thus take quite a while for enough people to come together to form a little team. I was therefore doing continual mental-calculations about speed and remaining distance all the way to the final checkpoint (which was about 7 miles from the end), to try to make sure I arrived there before sunset!

After all, I didn't need to finish the whole event in daylight. The rules say: "you can't leave a CP in the dark" but they say nothing about whether you'd be arriving at the next one in the dark! This was the loophole I was relying on (and personally I don't mind if I'm on my own at night), so I pressed ahead in my usual style of walking the uphill, running the downhill, and alternating between fast-walking and jogging for the flat bits.

The final stages



Check Point 6 saw us turn SW, to begin the final quarter of the event. It also meant that we finally had the wind behind us – what a relief! And any such relief was very welcome, as we now had the hills to deal with. It had been fairly undulating all the way round, to be fair. The IOW is a hilly place, and this had included a long climb earlier, up to The Needles. However, we now had 3 final headlands to go up and over,

each one bigger than its predecessor, on ever-tiring legs!

But I was mindful of the time marching ever on, so I kept pushing, getting up and down those first 2 headlands, to reach the final checkpoint (CP7). Having been on the go for 59 miles and 13½ straight hours of effort and maths, I arrived just 15 mins before sunset, so I didn't hang around! I grabbed a cereal-bar, filled my bottles, got my headtorch out of my backpack, and was gone again before there was time for anyone there to think about saying anything!



Andy on the final leg in fading light

The last leg was the biggest hill of the entire route (a fitting end to the event really), so you become very mindful of watching your step in the dark, not wanting to make a mistake at this late stage. I finally crested the top of that last hill over St Catherine's Point, and could see the finishing-point 2km away, a brightly-lit oasis in an otherwise pitch-black landscape. A very welcome sight! Just a jog down the other side still left to do, then I finally crossed the line, in 49th place, in a time of 15h 12m, just before 10pm. A new personal best for me for that distance (by some margin actually!). There's nothing like running for a good cause to spur you on!

My thanks go out to the event-organisers, but also especially to all the people who supported my endeavours. Without them, it would have been pointless. The money is still coming in, but even as things stand now, including GiftAid and a matched-donation from my employer, it's nearing £4000, so again huge thanks to everyone who has sponsored me. I was proud to wear the HSP Support Group's banner on my way round, and I wish you every success with all the good work you continue to do.

Andy Carpenter

Chairman's Column



I am writing this in the heat of the summer, and the AGM feels like it was a long time ago already. I'm going to use this column to describe what I said at the AGM, and to repeat the call for help that I made at the AGM. The main item to note is that of our five trustees, two have stated their intention to stand down from being a trustee at the next AGM. Therefore, there is an urgent need for the group to find new trustees to help run the group. I spoke with many at the AGM, several of whom said that they were going to go away and consider if they would become trustees. Now that we are some weeks after the AGM, I would be really pleased to hear from any of these people to help them with their decision-making process.

AGM: Mission Statement

During the year we agreed a new mission statement for the Group:

People with Hereditary Spastic Paraplegia (HSP), their families and carers are at the heart of everything we do.

- Our information and support help 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

AGM: Research Grant Process

During the year we also revised our process for the application of funds for research projects. We have prepared a new process which sets out our expectations, and we have set out seven questions for applicants to answer in order for us to evaluate if we wish to grant their application or not. The seven questions are:

- How will the research be used?
- How will the work improve quality of life?
- How long until the results are ready?
- Which types of HSP are covered?
- How will people be informed of the findings?
- How risky is the work?
- Will you publish the results whatever the outcome?

To begin with, the new process is being run as a trial.

AGM: Meeting Costs

The group has changed its approach to funding costs for regional meetings. Going forwards, by agreement, the group will fund costs associated with room hire for regional meetings. Those running meetings should agree any room hire costs with the group before the meeting takes place.

AGM: Ambassador

Amber Meikle-Janney agreed to become the first ambassador for the group, which should be a good way of helping to raise wider awareness of HSP and the group.

AGM: Helpline

It is with great sadness that Stephanie has decided to step down from running the telephone helpline for the group. I wish to thank Stephanie for all the hard work she has put in for the Group helping callers find out information about HSP. Stephanie has run the helpline for more than 30

years, since 1986. Many people are finding out more information using the internet, and the number of calls to the helpline has been reducing over recent years. We are looking at alternatives.

NICE Consultation into Cannabis Based Products for Medicinal Use

The next stage in the consultation into cannabis-based products for medicinal use is now open. NICE have published the draft guidelines, which indicate that cannabis-based products could be prescribed for people with HSP, but only as part of a clinical trial. This is principally down to the lack of evidence for these products being effective for HSP. I will be writing the Groups response shortly.

<https://www.nice.org.uk/guidance/indevelopment/gid-ng10124>

Christmas Shopping?

Have you started thinking about Christmas shopping? – If you do your shopping on-line then remember to use our easyfundraising page. We can receive a small percentage of your shopping at no extra cost to yourself. Start shopping through this page:

<https://www.easyfundraising.org.uk/invite/SBBB4F/>. Many companies offer a donation, including; Amazon, ebay, John Lewis, Argos, Next, Debenhams, Thorntons, Virgin Experience Days, Hawkins Bazaar, Cadbury Gifts Direct. Please tell your friends and family about this as well!

Conclusions: AGM reports, Spatax, and my 2019 Survey

Unfortunately, timings have conspired against me this year, so I am unable to give you either my write up from the AGM presentations, or give you the link to my 2019 survey. My write up for the AGM presentations will be included in the next Newslink. For those of you with an internet connection, I expect the AGM presentations to be on my blog by the middle of September, and I expect my survey launch to be up before the end of September.

<https://hspjourney.blogspot.com/>

During September I will also be attending the Spatax meeting to learn about current HSP research and I will also be presenting a poster with the results of my three most recent surveys.

Adam Lawrence

Editor's Column

You'll notice, as you read this edition of our newsletter, that I've had some excellent articles provided by members and friends.

Please keep these coming in: it makes the newsletter so much more interesting and it makes my job a lot easier.

I've recently had my annual trip to the National Hospital of Neurology in London to confer with the HSP specialists. It was my birthday so I decided to make the most of the day in London and make it as positive an experience as possible. I travelled up by train from Poole in great company. The boyfriends of my two daughters both travelled with me and good food and beer was planned for the afternoon and evening. I hear the occasional negative comments regarding the railways but I can't fault them. I've always been looked

after very well and the way there's someone always waiting at my destination with a ramp is impressive. I also must thank the member who suggested I get a disabled persons rail card. It paid for itself with the money I saved on that day's travel.

On arriving at Waterloo Station, we made our way on foot (me in my wheelchair) to Queens Square, a hike of just under 2 miles. I've done this before and it's an easy route across Waterloo Bridge and past the theatres along the Strand. I find it much easier than using the underground and it gives me the opportunity to see a bit of the city. We arrived an hour early which was part of the plan, so time had to be killed in the Queens Larder, an 18th century pub, close to the hospital.

My appointment went very well and I was delighted to be seen by Professor Henry Houlden. He gave me plenty of his valuable

time as I'd taken with me a list of questions and points for discussion. While I was there, I gave a skin sample for research and had the pleasure of bumping into a fellow HSP Support Group member.

The trip back home also involved a pub (or two) and a lovely Indian meal, so despite having a medical appointment, I thoroughly enjoyed my 56th birthday.

The Potato Pants Festival was another success this year. I changed the location and we were hosted by a local sports and social club, mainly because it's so much more accessible for disabled guests. The club loved the event and want to get more involved next year and maybe even make it an event for their 3000 members. I'll still be able to sell up to 500 tickets, so I'm hopeful that it may now start to raise some significant funds. This year was the first time that I've paid musicians and consequently, funds raised on the day were a little lower than usual at around £1000.

Clashing with the Champions League final also affected ticket sales a little. However, we'd done some fundraising for Potato Pants prior to the event and raised a further £2500, so financially the event was a success.

The music was excellent and guests agreed that it's a much better venue for accessibility than the previous site. The food and drinks were superb and I must thank the Charitable Emporium for their help with providing staging and sound. The Potato Pants Festival will definitely be held at Cobham Sports and Social Club again next year but to fit in with their busy calendar, it will be held in August and not June. Put August 15th in your diaries.

I'm delighted that the football season is up and running again. I'm a season ticket holder at AFC Bournemouth and they really do look after disabled supporters well. I sit at pitch level and I'm often spotted on Match of the Day, so look out for me in my silly red flat cap.

I'm still loving my weekly radio slot and I know some HSP members tune in. I find music is one of the best therapies for HSP.

You'll have read in Adam's column that Stephanie has decided to stop running the HSP Help-line. I'd like to thank Stephanie

personally as we have worked together for many years and it has been a pleasure.

It was great catching up with many of you at this year's AGM. Unfortunately I'm unable to attend the Devon meeting in Ashburton on October 19th because I'll be at a close friend's wedding, but I know it'll go well and I look forward to the next one.

Ian Bennett

Members Letters

My name is Nigel Bulbeck and I am a fellow HSP sufferer. I was diagnosed back in 1990 and then later joined the group. My condition has deteriorated over the years although I suspect old age (I am now 60) also has a part to play. One of the things I miss above all others is not being able to cycle. Up until about 10 years ago I would cycle regularly with my son and then as he got older and my condition got worse I moved to cycling at Alice Holt Forest where the CTC set up a special cycling group for people with disabilities. This was good and I thoroughly enjoyed my weekly session on a Thursday (my employer allowed me to change my working hours) but again my condition started to deteriorate and even laying the bicycle flat on the ground to "get on" was proving a bridge too far. Then last year after searching the Internet I found a group that provided cycling for the disabled and they had recumbent hand cycles. This appeared to be just what I was looking for.

This year (8th June) I went on my second annual visit and enjoyed it so much I felt I must share this experience with the Group. These two sessions I have attended are called taster sessions and are designed to get the novice interested in recumbent hand cycling. Not difficult with someone like me. The sessions take place at the Stoke Mandeville Athletics track which is adjacent to the hospital (postcode for SATNAV HP21 9PP). You will ride outside on the running track so weather conditions will play a big part. These sessions are organised by Matt Lindley (07553 930193) who is a wheelchair user but obviously also uses a recumbent. There are

also other helpers from British Cycling and Stuart Twigg who I will mention again a bit later.

The reason I am so keen to tell people about this activity is that it gives us the chance of a physical activity that some of us like me thought had passed us by. I will make it abundantly clear that this activity will not improve your HSP or make your legs move any easier. In fact your legs just rest down the side of the cycle as in the photo and it is your hands and arms that do all the work. However I get such a buzz out of being able to do something that I have always enjoyed that when I leave the session I am on a positive high. I am a strong believer in your state of mind playing a part in how you function physically.



Now the news gets better; I initially thought this was just an annual event where like this year I had to refresh on all the knobs and levers (don't panic. there aren't that many). No, there is a monthly get together on the third Saturday of each month run by the aforementioned Stuart Twigg (07747 047302). Lovely gentlemen, runs sessions for the children from the hospital (found that a bit emotional). He would love to see more people and has cycles to cater for all shapes and sizes. His sessions are 10.00am to midday and cost £10.00. The £10.00 will also cover a family group and is payable on the day. There is no annual subscription.

I appreciate that this will not be for everyone, especially as it will be too far away for some but Stuart has said that If you give him a call, he can point you in the direction of your local group.

Nigel Bulbeck

Scootering in the Countryside

Below is my report on a recent mobility scooter experience on the South Downs. I thought members may be interested in a route that was fully accessible with transport to the site, plus a cuppa and cake at the visitors centre next door!

I decided to book a basic short coach holiday in early April staying at the Queens Hotel, Eastbourne. Through them I hired a simple mobility scooter that was small enough to go on the coach and I could just use it for exploring the seafront and round town on non-driver led days. During the week I actually wanted to hire a robust off road scooter like a 'Tramper' somewhere near the South Downs Way within the national park so I contacted the 'Access and Recreation' department to ascertain if this was possible. Unfortunately I was told that there was no such outlet in the area. I was given the contact details of **disabledramblers.co.uk**. However, anyone would still have to own their own 'Tramper' and be able to get it to an area near the South Downs Way. There is another organisation that uses the countryside for the disabled and they are based in the West Country. Their contact details are: countryside-mobility.org. With my original intention not possible I was informed that the South Downs National Park have an initiative called 'Miles Without Stiles' and that Cuckmere Haven, a flood plain, an area where the river Cuckmere meets the English Channel near Seaford, within the 'Seven Sisters Country Park' was flat and suitable for mobility scooters, even a basic one.

This sounded great, but I would still have to get to the park from Eastbourne. I thought, no problem, the local buses are disabled friendly. Unfortunately I found out that this was only for wheelchair users. I had to find an alternative means of transport! After several phone calls the hotel managed to find me a taxi with a lift, so it was perfect. It was an accessible van from 'Wheelchair Transport Services'. The vehicle was brilliant!

I had a great day scootering along the flat trail, a 3 mile round trip, within the Cuckmere

Valley, heading towards the sea, with the stunning views of the South Downs to my left ie Birling Gap and Beachy Head and Seaford to my right.



Signpost on the route

Gary Cliffe (Orpington, Kent)

A very valuable gift - Thanks a Million

When you are first diagnosed, you enter a strange twilight zone between living the life you have always lived and a restricted one. It is the passing from daylight to darkness. Artificial lights flicker and buzz on in the rooms and houses of the new shadowy environment you have just moved into.

And then, after a few months of stumbling about, you finally resign yourself to this new existence: a life-changing event has occurred, leaving you to gather up the pieces of what had been going on before. Reminds me of the Black Sabbath lyric: 'I used to count in millions then, now I only count in one' in the album 'Heaven and Hell', 1980. You try to stay positive: onset, in my case, hit fairly late in life, the later this being, the slower the progression. And every day brings the usual stretching, strength and balance exercises in the hope that one-day new research will miraculously uncover a cure. You position yourself at the water's edge, waiting to see what the tide might wash up!

I'm sure you know this routine. A life-changing event, indeed.

Imagine, then, you have another life-changing event. Only this time it is for the good! My physiotherapist recommended I apply for a

grant to buy an electric tricycle. This would offer mobility to a life that has become tiny. No, microscopic. I always used to be a keen-but-casual cyclist, loving the freedom that the pastime offered. I would journey for miles, over hill and down dale, breathing in the fresh air of beautiful countryside. Anyway, I applied and within a short time, the trustees of the HSP UK Support Group, very selflessly allowed this dream-like image to become reality by funding the purchase of an electric tricycle. I'd also like to thank Tesco's of Blandford because I understand that they were the original source of this funding to be used locally.



John Mason (right) informing James Fitzgibbon about his award

To say I am very grateful is an understatement: what they have done is to grant me the gift of mobility, which is something that will allow me once again to count in millions. Once again, from my habitual sofa, I can set off and, for the time I have left, cycle and explore, feeling the wind on my face.

For this very valuable gift, I say thank-you for opening up once again horizons and for offering me back a life-style that I believed to be in the haziest past.

James Fitzgibbon

Fundraising News Please read this!

Since I publicised

[Easyfundraising.org.uk](https://www.easypublishing.org.uk) at our 2019

AGM, we now have 39 individuals raising funds for us using this facility

and we have raised well over £300.00.

We have nearly 400 members, and no end of friends, so we should easily be able to attract many more than 39 supporters and raise significant funds for HSP with Easyfundraising. If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. It's so easy to do. There is no catch: it really is a no brainer. For example, every time we do our supermarket shopping online with Sainsbury's, 50p goes to HSP. This alone raises £25 a year for HSP and I'm sure many of you do your supermarket shopping online. Other retailers pay us up to 3% of the value of purchase and even my eBay purchases earn the HSP Group 0.5% of the price I pay. We've just renewed an insurance policy on a car and if we'd realised that if we'd navigated to the insurers website, via the easyfundraising site, £10 would have been donated to the HSP Group.

There are thousands of retailers who support this including Amazon, Groupon and eBay, not to mention most high street stores. Use the following link and follow instructions:

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

As I said, any problems, give me a call but it's proving to be a great way of raising funds, we simply need to get more members and friends involved, and it really is simple.

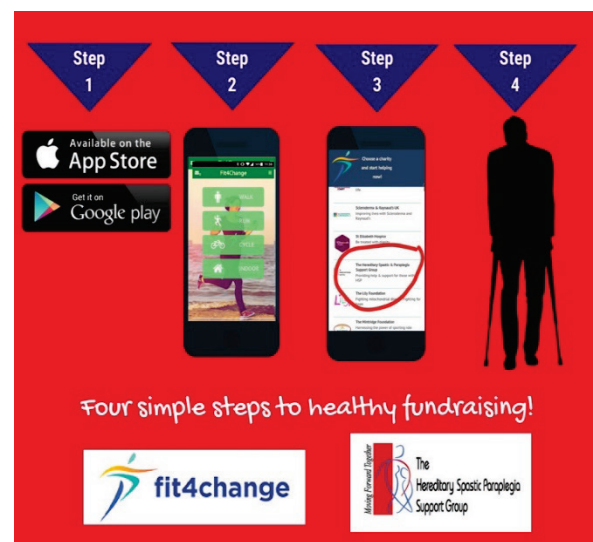
Many thanks to the 39 people who have already signed up to this great facility.

Ian Bennett

Raise 5p/mile with fit4change

If you know anyone who does a lot of walking or running, they can earn 5 pence/mile for HSP. I use it myself when training for the half marathon on my wheelchair and I just say I'm doing a run. It's very simple, all you need to do is download the Fit4Change App and make sure you have your phone on you and Wi-Fi/mobile-data on when doing the activity. GPS technology monitors the distance completed and the money your activity raises is paid from the advertising revenue

generated by the Fit4Change App. The App is available from: <http://www.fit4change.com/>



I raised over £10 when I was training for the Bournemouth half marathon in my wheelchair, using fit4change. If we could get a number of members and friends using this App, even if it's simply when they walk the dog, the money would add up. If members have friends who are runners, please pass this information on. Anyone can raise funds for HSP using this facility and it's very simple to use.

Fundraising Activities

There have been some fantastic fundraising activities in recent months and we can't thank all the participants enough for their efforts. I won't list all of them but I've highlighted a few below.

Simon Lewis and James Lane have both raised funds for us by climbing the three highest peaks in the UK.

Tobie Muir raised funds taking on the Singu Chuli Peak Challenge in the Nepali Himalaya range.

On June 22nd Christine Shepherd climbed ten mountains in the Lake District in ten hours

Claire Diffin ran this year's London Marathon for us and you'll have already read about Andy Carpenter's challenging activity at the Isle of Wight on the front of this newsletter.

Kathryn Lindsay raised money for us at this year's AGM selling the jewellery that she makes.

Amber Meikle-Janney's Grandfather gave a talk to his Rotary club and raised funds for us.

You'll have read about this year's Potato Pants Festival in my column.

Caroline Begg raised funds by taking part in the SuperHero Triathlon at Dorney Lake in Windsor.

There have been many small donations of £100 and under and we have an ever-increasing number of collection buckets in pubs, restaurants and garden centres.

Thanks to everyone who has raised funds for our charity. We guarantee that we will make great use of all funds raised, either for research purposes or for the benefit of members who may need a little assistance with mobility issues. If fundraisers have a preference what their money is used for, we will always honour their requests.

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 £750. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Regional News

Spring meeting at Milford.

Circumstance determines that some are able to join us for every meeting, whilst for others, a particular day of the weekend or time of the year is best for them. We are fortunate in that many who cannot join us let us know in advance, so we can update those attending with their news, especially if they are used to seeing them once a year. But, it is always good to see anyone who is able to travel to Milford.

Eddie told us the latest news from Utility Warehouse with John, who has been an Utility Warehouse customer for some years, explained how he continues to benefit. Rob had kindly brought his 'Alexa' with him. We all had a lot of fun experiencing the possibilities that Alexa could provide. This was expounded when some wanted to listen to the Grand National later in the afternoon!

Following the part of the afternoon where carers have time to share, I explained that not through want of trying, I had been unable to gain a speaker for the afternoon, to explore the benefits of CBD oil. There have been numerous discussions concerning the alleged advantages of using CBD Oil on HSP sufferers. We did have a lively exchange of information from members who were using, or had been using, CBD oil and those who were interested in its use.

We ended the afternoon with our usual refreshments, a raffle and plenty of chat, before members made their way home.

For our November meeting, we are hoping that Richard will tell us about his use of Orthotic underwear. We can't wait.....

Wishing you all a good summer, best wishes,
Mike and Jane Bennett

Colchester Branch Meeting

We gathered at Feering, near Colchester in Essex in October 2018 for our Autumn meeting. There were 22 of us, chatting over tea, coffee and biscuits and listening to our speakers, Jo and Steve, who came from Colchester Hospital to talk about falls.

Jo has a background as an occupational therapist and warned us of all the risk factors for falls, from tripping over the cat to dehydration. It turned out that there are many, many risk factors. In particular, she mentioned the importance of wearing well fitting shoes and taking good care of our feet with visits to the podiatrist when necessary.

Steve then talked about assistive technologies – call buttons and pendants. He explained that they can be used, both by people who live alone to call a careline operator who will

organise help and by those who live with family or carers to call someone in another room. Steve emphasised that, with a fall, the key issue is how long someone remains on the floor. The longer on the floor, the longer any stay in hospital is likely to be and the greater the risk of a poor recovery.

Jo and Steve finished with a demonstration of the best way to get up from a fall, for those that can. For those that can't, they showed us the correct use of a Mangar Elk raising cushion which requires help from another person. Ambulance crews will normally carry a raising cushion for such circumstances.

Our next meeting was on Sunday, 24th March 2019 when Adam Lawrence, Chairman of the HSP Support Group, came from the other side of the country to join us. This was one of our best attended meetings.

Adam updated us on the latest published research into HSP while explaining that there are gaps in the field which still need to be addressed with good quality research.

However, a diagnostic flow chart is being created to improve the speed of and rates of diagnosis. Work is being done on the benefits of stretching and one team is hoping to develop a physical activity routine for a range of conditions including HSP and MS (The PARCC team -

https://twitter.com/parc_community). Work is continuing on identifying biomarkers which can be used to measure the effectiveness of treatments for HSP as they become available. Specialists in HSP regularly meet together to promote understanding of the field and to cooperate with one another in their research. Adam also told us that the NICE guidelines for cannabis-based drugs have been widened to include all spasticity with the result that spasticity from HSP is covered. Carina Thurgood also updated us on other current research which she has recently been discussing with scientists.

Adam explained the way in which the HSP Support Group assesses requests for research funding via a research committee which scores applications and then reports to the

Trustees of the Group, who make the final decision.

The Trustees are in the process of revamping the website and Adam would welcome photographs of members doing something exciting that can be incorporated into it. He would also like to hear from members with any tips that have helped them so that they can be made available to anyone visiting the website.

We also had a wide ranging discussion covering a number of other areas.

We are very grateful to Adam for travelling so far to join us. It was a wonderful opportunity to hear more about the latest research and all the work the Trustees of the HSP Support Group are doing for us, especially as the majority of members who attend the Feering meeting are unable to go to the AGM in the summer.

Thank you also to all the members who help with the meeting in a variety of ways.

Our next meeting is on Sunday, 20th October 2019 from 2.30 pm-5 pm at Feering Community Centre, near Colchester, Essex, CO5 9QB and, as always, everyone is very welcome to join us.

Hilary Croydon

Norwich Get Together

The small group of Norwich members of HSP met on Saturday 21st July. We hoped to have a 'garden party' in my garden but the weather wasn't in our favour, so we sat in my lounge and enjoyed tea and cakes. We had a Bring and Buy sale among us selling beautiful needlework and plants. The sale went well and the money raised has been sent to HSP funds. After a lot of talking on lots of subjects, the meeting closed.

Barbara Jones

Forthcoming Events

Hitchin Get Together

Saturday 14th September 1.30pm – 4.30pm
The Orange Tree pub
100 Stevenage Road
Hitchin
SG4 9DR
Call Della Brookman on: 07710 637 941

Stockport Meeting

Saturday 21st September 1.30pm – 5pm
Quaker Meeting House
2 Cooper Street
Stockport, SK1 3DW
(For sat Nav use: SK1 3QL)
Call Irena Pritchard: 01524 261 076 or
Mike Cain: 01614 567 531
Irena.pritchard@btinternet.com

Birmingham Meeting

Sunday October 13th 11am – 3pm
The Kenrick Centre, Mill Farm Rd, Harborne,
Birmingham. B17 0Qx
Contact Penny Cohen on 07818 288 738
Or June Masding on 07500 584 681

Ashburton Gathering

Saturday October 19th 2pm onwards
The Dartmoor Lodge Hotel
Peartree Cross
Ashburton
Newton Abbot
TQ13 7JW
Call Ian Bennett on: 01202 849 391

Colchester Meeting

Sunday, October 20th 2.30 - 5pm
Feering Community Centre
Feering
Essex
CO5 9QB
Call Hilary Croydon: 01284 728 242
tohiti@btinternet.com

Milford Afternoon Tea South/South East

Sunday November 17th 3pm – 6pm
The Clockhouse
Milford
GU8 5EZ
Call Jane Bennett on: 020 8853 4089

New Members

We welcome the following new members:

Ashley Pike Wellington	Jane Jarman Bridgnorth	Sarah Rannard Wirral
Ben Whittle Long Eaton	Lisa Wyan Rugby	Siang Ing Lee Birmingham
Estelle Marshall Burnley	Mehmet Komesogutlu London	Suzette Nelson Dunstable
James Fitzgibbon Frome	Philippa Lee Warrington	Tom Blake Blandford

If you are interested in contacting any of the above new members, please contact the membership secretary.

Useful Contacts

	Email	Telephone No:
Adam Lawrence - Chairman 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	adam@idios.co.uk	07834 505 161
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
Ian Bennett – Membership Sec / Newsletter Editor 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechonovember@btinternet.com	01202 849 391
Jane Bennett – South / South East co-ordinator	luckyjane82@hotmail.com	020 8853 4089
Della Brookman – Herts co-ordinator	della_brookman@msn.com	07710 637 941
Penny Cohen – Birmingham co-ordinator	pennycohen57@hotmail.com	07818 288 738
June Masding – Birmingham co-ordinator	june_masding@hotmail.co.uk	01214 445 095
Mike Cain – Trustee & North West co-ordinator	michaelcain123456@yahoo.com	0161 456 7531
Irena Pritchard – North West co-ordinator	irena.pritchard@btinternet.com	01524 261 076
Hilary Croydon - Colchester co-ordinator	tohiti@btinternet.com	01284 728 242
Barbara Jones – Norwich co-ordinator		01603 423 267
Liz Redmond - Neurogenetics Nurse based at The National Hospital of Neurology & Neurosurgery	Redmond.liz@uclh.nhs.uk	02034 484 487