

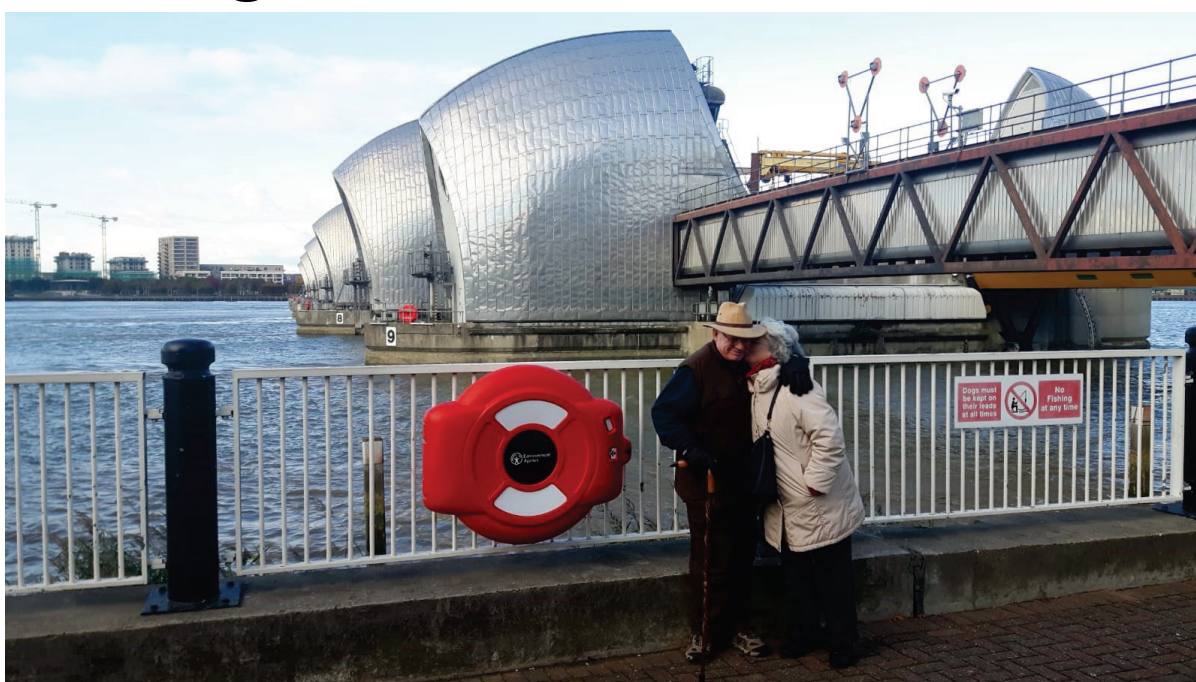
# HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 46 – March 2019

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

## Walking the Thames Path with HSP



Anne and Michael Horsman at the Thames Barrier, the finishing point of their 184-mile walk

**I found out in the 1990s, in my forties, that I had HSP but I am one of the lucky ones** in that while I limp heavily and am slow and clumsy in my movements, I can still get about with the aid of a stick, and the disease is progressing only slowly. I got about and got most of my exercise with cycling (since 2012 with an electric bike) but I understood that I had to walk as well however difficult it might be. Use the legs or lose them!

Then in 2010 I had a heart attack. I made a full recovery and I resolved to do a big

target walking. I chose to attempt the Thames Path.

The Thames Path is 184 miles from Kemble, near Cirencester, to the Thames Barrier near Woolwich in south-east London. It's a walk through English history through places like Oxford, Windsor, Henley, Runnymede and of course London itself. At Cricklade, 20 miles from the source, you walk through the remains of Saxon fortifications more than a thousand years old; a few miles further on, at Lechlade, you see the concrete gun emplacements of "Stopline

Red” the defensive line put up in 1940 to keep an invading German army out of the Midlands. You pass the house of William Morris the artist and the other William Morris the car manufacturer. You pass Windsor Castle and Hampton Court and Shakespeare’s Globe and the Tower of London. You pass too many marvelous things to describe in a short article. But how to do 184 miles when you walk like a Long John Silver impersonator?

The first consideration was, know your limitations. There was no chance whatsoever I could do it without assistance. So my wife Anne walked every step with me. In fact, she probably walked the Thames Path plus at least 30 per cent because in the early stages where there was little public transport; we often left the car, walked a few miles then Anne left me exhausted at some pub or teashop while she walked back to the start point to get the car to drive me home. We also decided to do the path in small portions. We would take two or three days, staying in a pub or guesthouse, walk what I could walk, and go home. The upside was we got to know many excellent hostelrys to some of which we have often returned!

It was a truly great experience but those who have HSP will understand me when I say it was many times unspeakably exhausting. It became a house rule that after a Thames Path excursion I had a recovery day in which I did nothing. And of course over the eight years my HSP progressed. In 2010 I might have managed five or six miles in a day before near-collapse; by 2018 the absolute maximum was about two miles.

So on 28 October 2018 the Horsman family (myself, Anne, two sons, a daughter-in-law, and a granddaughter not yet five months old) assembled at the Pilot pub in the Greenwich Peninsula to walk together the last two miles of the Path. It took us nearly three hours, but we made it. I limped along supported by a stick on one side and a family member holding my arm on the other. Yes, I was ultra-tired but it was a wonderful experience. And at the end, at the Thames Barrier the true heroine of this monster effort leaned over and gave me a kiss; and with that picture eight years of planning and hoping and walking came to an end.

**Michael Horsman**

## Chairman’s Column



I’m pleased to spot that the days are getting longer and there is life coming back into those plants which have been sleeping over the winter. I find the spring a positive time, and the longer daylight gives me energy to get more things done. The end of February saw Rare Disease Day, and you can read a summary the results of my survey at the end of this newsletter. Thanks to all who filled it in. My attention now turns back to sorting out the AGM and helping the group to move forwards with the actions we agreed at the trustee meetings.

## New Constitution

I am very pleased to report that following the AGM in 2018 where we voted to change the constitution of the group, the new constitution has been accepted by the Charities Commission and we are now registered as a Charitable Incorporated Organisation (or CIO for short). To remind people, we needed to update the objectives to reflect what we currently do and that put us on a much longer journey revising the whole constitution. My thanks go to John and Dave for their sterling work completing this mammoth task. Our new charity number is 1181539, and all other details remain the same.

## AGM

A quick reminder that the 2019 AGM is on Saturday 13<sup>th</sup> July in the Tally Ho conference and banqueting centre – the same venue as 2018 and 2017. I look forward to seeing lots of you there. At the AGM I will give you an update on the progress on the list of preferences you expressed at the 2018 AGM and which I set out the last Newslink.

## NICE Consultation into Cannabis Based Products for Medicinal Use

In December 2018 I submitted a response on behalf of the group to the NICE Consultation into Cannabis Based Products for Medicinal Use. This phase of the consultation was to help shape the scope of the guidelines, and the consultation has widened the scope of the guidance to include all spasticity and to consider allowing cannabis based medicines to be prescribed off-label. The guidelines themselves will be written during 2019 and I will submit a response to the draft guidelines themselves when they come out for consultation.

It is good to see the support group as a stakeholder in the consultation process, which raises awareness of us and HSP. You can see all the consultation responses on the NICE website: <https://www.nice.org.uk/guidance/indevelopment/gid-ng10124>

## Helping the Group

In the last Newslink I suggested three areas where people could help the group – fundraising, attending meetings and increasing our engagement with our younger members. I'd still be pleased to hear from people about this – especially if you know anyone who set themselves a new years resolution around helping other people (not necessarily on those three topics). Whilst it is nice for people who help to have a connection with HSP I'd be keen to hear from anyone with a passion to help. I'm happy to have a chat with anyone.

## Summer Holidays

Have you booked your summer holidays yet? – If you book these on-line then remember to use our easyfundraising page. We can receive a small percentage of your holiday costs at no extra cost to yourself. Start your booking through this page: <https://www.easyfundraising.org.uk/invite/SBBB4F/>. Many companies offer a donation, including; EasyJet, Tui, Lastminute, Air France, Thomas Cook, Haven, Virgin, Mark Warner, Hertz, airport parking and much more. Please tell your friends and family about this as well!

## David Pearce

Many of you will remember reading about David Pearce's death in the last edition of Newslink. Since this time we have heard from his solicitors and David left the group a substantial bequest in his will. We will need to decide the best use for this money.

**Adam Lawrence**

---

## Editor's Column

A very belated happy new year to all of you.

I mentioned in the previous Newslink that I'd entered the Bournemouth Half Marathon in my wheelchair, in October last year. It was quite an experience and I really enjoyed being

the only wheelchair amongst thousands of runners. Partly because the weather was perfect and partly because I trained properly for months before, I did it twenty minutes quicker than my best expectations, beating many runners in the process. I was delighted to have raised £1300 for charity which worked out at £100 per mile, and thank you to all of

those who supported me. I will continue keeping fit in a wheelchair and probably enter again next year. As soon as the weather improves a little, I'll return to having weekly training sessions on Bournemouth promenade. There are worse places to train.

I've now settled being a DJ on a local radio station and I'm loving it more and more. The show highlights the quality of local music that we have here in Dorset and Hampshire and I now have well over 50 musicians in my database. I always thought I knew a lot of local musicians but I've now got to know even more. It'll be even easier now to attract artists to perform at the Potato Pants Festival on June 1<sup>st</sup>. If you're interested in listening, my show is called 'Wired' and all my shows are saved on [www.mixcloud.com](http://www.mixcloud.com) Search for 'welcome2wired' and you should find my shows.

Since the last edition of the newsletter I can report a new addition to my family. A couple of months ago we adopted a stray cat and although I've never really wanted pets, I am really enjoying her company. She was very timid to begin with and I suspect she'd been mistreated, but she's gradually getting bolder and bolder. I'll keep my fingers tightly crossed that she keeps away from the busy road.

Great progress is being made in planning this year's Potato Pants Music Festival. This year we'll be at a new venue which is a sports and social club on the edge of Wimborne. We'll be having two stages and there are two bars, one of which will remain open until midnight. I'm receiving great local support which is enabling me to keep costs to a minimum. This year the website is much better than it has been in the past, thanks to volunteers. You can keep up with progress by visiting [www.potatopantsfestival.co.uk](http://www.potatopantsfestival.co.uk)

I've also planned a warm up event for Potato Pants in my local pub which is called The Old Thatch. Some of you will know that this pub has been very generous in supporting us in the past. This event will take place on April 13<sup>th</sup> and will involve three musicians who will also be involved in the Potato Pants festival on June 1<sup>st</sup>. If weather permits, we'll organize a couple of potato pants races up the quiet

lane at the side of the pub. The main purpose of this event is to raise local awareness of the Potato Pants Festival, but we'll certainly have a few collection buckets on the bar and hopefully raise a few pennies. It would be great to see some fellow HSP'rs there.

I'm delighted that Spring is finally here. January and February always seem to take a long time to pass by, but now that they have done so I can spend more hours enjoying the garden and getting out and about more. I definitely find that spending more time outside makes me feel better and I'm sure that is true for most of us.

Thank you to those who have contributed to the content of this newsletter. Please continue to do so as it makes it a far more interesting read, when we learn about each other's experiences. It would be very nice to hear from members who haven't contributed in the past. Particular thanks to Adam for providing us with the very interesting results of his comprehensive survey, which you'll find towards the end of this edition.

I'd like to finish by wishing Claire Diffin all the best for the massive challenge she's soon to undertake for HSP. The London Marathon is tough and earns my full respect. I know because I've done half marathons in the past and was very involved in my daughter Jade's preparation and participation in the event last year. You'll read a few words from Claire later in this newsletter explaining why she's taking on this challenge. On behalf of all of us Claire, good luck, enjoy the amazing event and thank you!

***Ian Bennett***

## **Brooke's night out in the City of London**

There was a party of twelve of us, all going to London to celebrate a good friend's birthday. My wife Kim left from a local train station called Whytlee, travelling on a Southeastern train to London Bridge. I was travelling with good friends Terrie and Dave. Although the station we used was un-manned, this didn't cause too much of a problem. Dave and a



passenger were able to lift my mobility scooter on to the train and when we arrived at London Bridge, Kim and Dave lifted it out of the train. We set off to meet our friends at the Walkie Talkie building for a quick drink in the Skygarden and take a look at the views of the London skyline at night. There were no problems with accessibility on my scooter and there were easy access disabled toilets.



Brooke on top of the Walkie Talkie building

We then made our way to Swingers for an evening of indoor golf. It was a super night with really helpful assistance. There was a chair lift to get down to the golf course. All the staff were super friendly and couldn't do enough for me.

We set off for a walk (me on my scooter) back across London Bridge to the train station. On boarding the train, I was able to drive straight on because they had a raised platform for wheelchair access. This was part of the multi-million-pound refurbishment of London Bridge Station. When we arrived back at East Croydon, we were fully expecting to be able to ride my scooter straight off the train. Surely the rail company wouldn't provide special wheelchair access features at London Bridge, without continuity at all stations on the line. How wrong I was. You guessed it! There was a great big gap between train and platform at East Croydon. Fortunately, I was travelling with a group, so my scooter was lifted off the train. We all headed towards the

lift but unfortunately the lift was out of service.

After a great night out with friends, we felt let down by the rail network. It's an absolute disgrace! They have a long way to go in providing a dedicated service for the disabled community.

That's all for now folks. I will let you know the outcome of my formal complaint

**Brooke Wyatt**

## Terry Reed



It was very sad to learn of the recent passing of Terry Reed, a lovely man. Terry has been a very pro-active member of the HSP Support Group since 2004 and has been a regular at meetings together with his wife Pat. I've enjoyed Terry's company at almost every AGM since 2004 and have also seen him at other events including a Motability Road show at Kemble airfield several years ago where it was a privilege to organize a flight in a light aircraft for him. Both Terry and Pat have always been lovely company and many of our members will know them and be very sad to hear this news.

Although Terry had both Parkinson's and HSP he was always cheerful and keen to socialize. Terry died peacefully at his own home with Pat at his side.

Terry will be sadly missed by many of us but his engaging personality and smiling face will never be forgotten.

**Ian Bennett**

# Fundraising News

## Fundraising that most of us can get involved with

Since I publicised

[Easyfundraising.org.uk](http://Easyfundraising.org.uk) at our AGM last year, we now have 36 individuals raising funds for us using this facility and we have raised over £200.00. We have nearly 400 members, and no end of friends, so we should easily be able to attract more than 36 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 shop online with Sainsbury's, 50p goes to HSP and other retailers pay us up to 3% of the value of your purchase. We've just renewed an insurance policy on a car and if we'd realized 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.

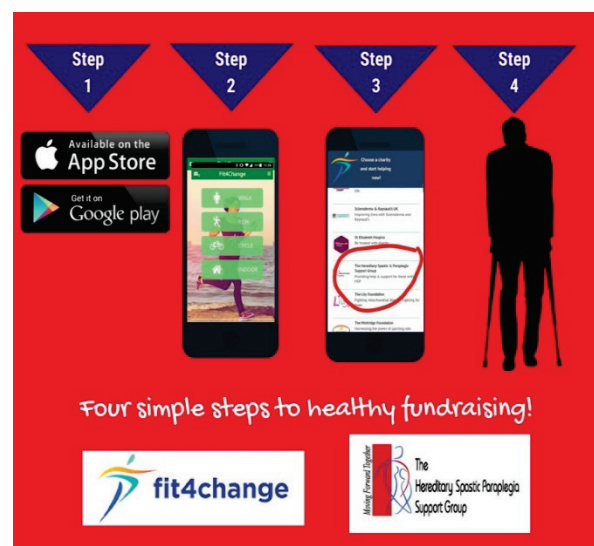
Many thanks to the 36 people who have already signed up to this great facility.

**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.

## Tesco – Bags of Help

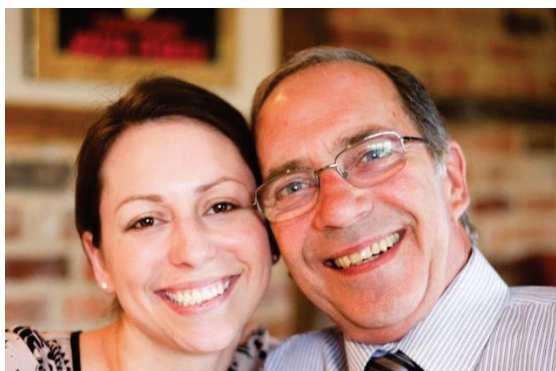
Bags of Help is Tesco's exciting local community grant scheme where the money raised by the sale of carrier bags is being used to fund thousands of local projects in communities right across the UK. Projects that bring benefit to their community will get the green light – these range from improving community buildings and outdoor spaces to buying new equipment, training coaches or volunteers and hosting community events.

Following a carefully worded application, the HSP Support Group has recently been awarded £2000 to support the work of the Potato Pants Festival.

## HSP fundraiser running in the London Marathon

Running the London marathon has been on my bucket list for years and after trying many times to get a ballot place I am delighted I was successful this year!

The benefit of getting a ballot place is I can raise money for The HSP Support Group rather than one of the mainstream charities. My father has HSP and I have watched his condition slowly get worst over time, he is now in his seventies and needs round the clock support. I don't know yet if I have inherited it but either way, I am desperate to do as much as I can to raise money for research.



Claire and her Dad

So what better challenge than running 26.2 miles! I've been training very hard to get myself ready to run my first marathon, and have also entered 3 half marathons (Richmond, Wokingham and Reading) and a 20-mile race (5 laps round Dorney lake!) as prep. I'm not giving myself a time goal for the marathon, my primary goal is to cross the line, enjoying the amazing atmosphere of the London marathon as I go, and to pick up that medal at the end which I can share with my family.

My fundraising has been going very well and it's so heart-warming how generous my family, friends and colleagues have been. If you are able to support or share my fundraising page that would be amazing <https://uk.virginmoneygiving.com/clairediffin> hopefully together we can find some answers.

**Claire Diffin**

## HSP Jewellery

I was shown how to make earrings at a craft day and loved every bit. From that I've learnt how to make other items of jewellery - such as bracelets and necklaces. I'm now expanding and using more techniques to make each new piece original with lots of colours and materials.



I find it really relaxing working with all the mix of colours and shapes, then designing new items.

The bracelets range from £1.00 - £5.00 and the necklace's range from £5.00 - £15.00. Each item I sell I'm donating 50% to HSP.

**Kathryn Lindsay**

[hspjewellery@outlook.com](mailto:hspjewellery@outlook.com)

## 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

### Hitchin HSP 'Get together' Saturday 26th January 2019

Our 'Get together' was a successful one, as all seemed to have had a positive time and chatted to other members.

We had a group of about 14 people attend and welcomed new members who had their first experience of attending an HSP meeting. We had to do a bit of table juggling, to get everyone together but, I am pleased to say they enjoyed the afternoon & hope to see them at the next meeting, which will be held on Saturday 14th September 2019 at the same venue. At this time, it seems the best place to hold the get together as access is good, no steps and has the necessary facilities. Also, there is no rush to finish one's lunch to move along to the next customers. Very relaxed and the staff will help, if they can.

Thank you to Terry for showing his lightweight wheelchair and attachment that turned the wheelchair into a trike, to other members. Some even had a try out in the carpark. Lots of help and ideas were swapped and everyone seemed happy. Looking forward to the September Get together and hope to see fellow HSP'rs there.

**Della Brookman**

### November Meeting at Milford

We were very pleased to welcome all those that travelled to Milford in November. Following a short catch up session relaying news of those that were not able to join us, Eddie shared an update on Utility Warehouse, especially as we had new members' attending. This was followed by Terry telling us about the

Calvert Trust holiday he enjoyed plus a demonstration of his electric wheelchair. These preliminaries were followed by non-affected family, friends and carers having time alone, to share information and knowledge.

Bethan Williams, who had joined us at our April 2017 meeting, is an occupational therapist specialising in neurology and her colleague Lit Eziefula, an experienced clinical psychologist, who works with clients with neurological conditions, spoke about fatigue management. They both have considerable experience in this field and managed to condense the content of their six week course into just under an hour!! Fortunately, there were handouts for all to take home and contact details if members wanted more information.



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

I have been in contact with a company regarding the medical use of CBD oil for the April 2019 meeting. I cannot say 'watch this space', but details of the April meeting will be posted in the HSP Facebook page.

Wishing you all a good summer, best wishes

**Mike and Jane Bennett**



## Facebook HSP Groups

We have the 'Hereditary Spastic Paraplegia's Unite' & 'Hereditary Spastic Paraplegia Support for UK HSP'rs'.

The 'Unite' Group is worldwide & has over 2000 members. Helping people who live with HSP from lots of different countries, to connect with others that know what living with HSP is all about. To share information/offer help and encouragement, to chat & support each other on good and bad days.

The 'UK HSP'rs' group is mainly for UK based members. At present we have 323 members & 309 active members. We encourage stories of what members are doing to raise funds for HSP, about their achievements in their daily lives, offer help/information caring and sharing all that would benefit HSP'rs, again on good and bad days.

The administrators try to monitor the pages and make sure all is running smoothly. If there is a problem then please contact any of the admin, who will try to help/rectify any issues.

I know some may be worried about using the internet to reach out in this way. Remember, you do not have to accept people's 'add friend Requests' or give information that you do not feel happy with divulging. You can contribute as little or as much as you wish to. Some visit and just watch what is being discussed, some visit the groups now and again. It really is up to you.

Each group has a set of rules that are shown when joining & there is a description pinned at the top of the sites page.

We would like to welcome you to any of the groups. Or both of the groups. It's up to you. I hope to see you there. :)

Here are the links to the two groups.

You do have to be a member of Facebook to access these group.

Hereditary Spastic Paraplegia's Unite

<https://www.facebook.com/groups/19469684343>

Hereditary Spastic Paraplegia Support for UK HSP'rs.

<https://www.facebook.com/groups/731239283741617>

## Della Brookman

### Rare Disease Event

The HSP Support Group is a member of Genetics Alliance and each year they have a reception at the House of Commons to mark Rare Disease Day.

This year I was invited to mingle with the great n good with wine and canapés on the terrace of parliament.

Mary Bythell of NHS England recognised me and we spoke for a long time. We spoke about the need for consistent treatment and perhaps an 'expert centre' to which all cases notes of specific rare diseases are passed while patients are treated locally. NHS England has this in hand and I am pleased to say that when Baroness Blackwood got to speak, she mentioned Hereditary Spastic Paraplegia and explained what it was to the people assembled which included Pembers and MPs as well as the All Party Committee of medicines.

It was a sunny day so the view from the terrace was great and the police were fantastic, providing a guard as they cleared a way through the crowds for me on the way in and found a taxi on the way out. I felt quite important – as HSP'rs should feel.

## Mike Cain

## Results of an On-line Survey for People with Hereditary Spastic Paraplegia (HSP) about Symptoms, Sleep, Activities of Daily Living, Support and Diagnosis.

This year my on-line survey was completed by 304 respondents with Hereditary Spastic Paraplegia (HSP) predominantly from the USA, the UK and Brazil. This is a summary of the findings. You can find more details on each section on my blog: <http://hspjourney.blogspot.com/2019/02/2018-survey-results.html>

Around one third of respondents had been diagnosed with another condition before HSP. Six conditions were listed at least five times and are likely to be misdiagnoses; Cerebral Palsy, Multiple Sclerosis, Ataxia, Arthritis, Herniated disc and Neuropathy. Around one third of respondents are living with multiple long-term health conditions. There were five conditions affecting at least five people: High blood pressure, Depression, Arthritis, Asthma and Diabetes.

Using the Warwick-Edinburgh Mental Well-Being Scale the average wellbeing score for respondents is 45.9. This is lower than UK population norms however it is still within the “average” definition and similar to those with a self-perceived health status of “poor”. There was no significant difference in wellbeing for those people who have additional long-term health conditions compared with those who do not.

### Mobility

The results show that just over half of respondents use walking sticks/poles/crutches/ canes and almost two fifths use wheelchairs/mobility scooters and walking frames/rollators. FES is the mobility aid used by the least number of people, with a take-up of less than 5%. Broadly these results are similar to those from previous years. Table 8 shows these results, including the percentage of respondents. These add to more than 100% as some people use more than one type of mobility aid.

**Table 1 – Use of mobility aids**

Mobility Aids Used - Summary:	Respondents	Percentage
Using sticks/poles/crutches/canes	167	55%
Using Wheelchair/Mobility Scooter	114	38%
Using Walking Frame/Rollator	86	28%
Using Orthotics/AFO	62	20%
Using FES	8	3%

This shows that there is a wide range of mobility aids used by the respondents to the questionnaire, covering all mobility scores. Overall the results are similar to previous years with broadly an even split between bands. The use of mobility aids allows respondents to be grouped together so that patterns and differences can be explored. These results are then simplified into five groups;

**Table 2 – Overview of mobility aids used**

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score	Wellbeing
Those without aids	60	20%	0-1	47.6
Those who use mobility aids some of the time	69	23%	2-3	47.7
Those who use sticks most/all of the time	105	35%	4-5	44.9
Those who use frames most/all of the time	33	11%	6-7	46.2
Those who use chairs most/all of the time	37	12%	8-9	41.9

The wellbeing scores for those using chairs all or most of the time is lower than the average score, suggesting that those who use chairs all or most of the time have a lower wellbeing than typical, however this is in contrast to the results in the 2017 survey.

When recalling changes in mobility over five years, around 20% of patients may experience significant changes in mobility. The quicker a person's change in mobility the lower their wellbeing is likely to be. A longitudinal analysis of 38 respondents who completed surveys over four or five years shows most have a low change in mobility over a four or five year period, and less than 10% have a high change in mobility over this period.

## Symptoms

The 2013 survey asked people to identify how much each of 13 different HSP symptoms affected them. For this survey the list has expanded to 36 symptoms, and respondents were asked to identify how each affects them, selecting from a list of answers, which have been grouped together to aid the analysis.

**Table 3 – Answers and Symptom Grouping**

Answer	Grouping
Do not have	Do not have
Occasional symptom	Minor symptom
Minor symptom	Minor symptom
Frequent symptom	Moderate symptom
Regular symptom	Moderate symptom
Most of the time	Major symptom
All of the time	Major symptom

The symptoms were sorted by overall impact, taking more account of the number of people who have the symptom all the time or most of the time than the number of people who have the symptom as a minor or occasional symptom. When sorted in this way there are five symptoms affecting almost everybody (loss of balance, muscles being stiff, difficulty running, difficulty walking, and difficulty using stairs).

**Table 4 – Symptom Impact**

Symptom	Major	Moderate	Minor	Don't have
Difficulty running	86%	5%	9%	1%
Difficulty walking	70%	16%	13%	0.3%
Difficulty using stairs	63%	17%	18%	2%
My muscles are stiff	60%	21%	18%	1%
Loss of balance	55%	24%	19%	2%
Get more stiff when it is cold	55%	19%	20%	5%
My muscles are weak	51%	25%	20%	4%
Fatigue	40%	28%	24%	8%
Affected by bladder problems	37%	19%	23%	22%
Back/hip pain	32%	23%	28%	17%
Leg/foot pain	33%	21%	26%	20%



Clonus (jumping feet or other muscle spasms)	24%	29%	33%	13%
Stress	23%	29%	30%	18%
Regular falls	16%	26%	45%	12%
Poor co-ordination	23%	20%	35%	22%
Pes cavus (arched/high feet)	27%	8%	15%	50%
Depression	15%	21%	35%	29%
Hammer toes (toes curl under)	24%	11%	15%	51%
Affected by bowel problems	18%	16%	24%	41%
Loss of vibration sensitivity in legs	18%	14%	27%	41%
Numbness	13%	20%	33%	34%
Pins and needles	9%	19%	34%	37%
HSP affecting sexual function	16%	13%	22%	49%
Feet swell up	14%	13%	29%	44%
Get more stiff when it is hot	11%	14%	32%	43%
HSP affecting learning or memory	12%	12%	26%	50%
Fail to remember dreams	14%	9%	22%	55%
Legs swell up	10%	11%	22%	57%
Stiffness/spasticity in arms/upper body	10%	10%	24%	56%
HSP affecting speech	10%	8%	18%	65%
Difficulty swallowing	6%	11%	19%	63%
HSP affecting vision	9%	6%	18%	68%
HSP affecting hearing	5%	4%	14%	77%
Ichthyosis (widespread persistent thick, dry, "fish-scale" skin)	3%	6%	14%	77%
Changes in perceptions of smell/taste	3%	6%	12%	79%
Epilepsy or seizures	1%	1%	6%	92%

Respondents also described which symptoms gave the greatest effect or had the biggest impact. This table shows those greatest effects reported by more than 10 people:

**Table 5 – Greatest Effect Symptom**

Symptom with greatest effect	Respondents
Fatigue	99
Difficulty walking	64
Loss of balance	53
My muscles are stiff	41
Affected by bladder problems	40
Back/hip pain	39
Stress	29
Depression	24

HSP affecting learning or memory	24
My muscles are weak	21
Clonus (jumping feet or other muscle spasms)	19
Affected by bowel problems	16
Numbness	16
HSP affecting sexual function	14
HSP affecting speech	12
Leg/foot pain	11

Fatigue has the greatest effect for about a third of respondents. Difficulty walking and loss of balance each affect about a fifth of respondents. Muscles feeling stiff, bladder problems and back/hip pain each affect approximately a sixth of respondents the most.

Three symptoms (depression, stress and affecting learning or memory) show significant negative wellbeing effects, and three symptoms show potentially significant negative wellbeing effects (poor co-ordination, regular falls and back/hip pain). It is interesting to observe that fatigue is the factor which is singled out by respondents as having the greatest effect, however depression is the symptom which has the greatest influence on wellbeing.

Of the 21 highest impact symptoms, all respondents had at least 5 and no respondents had more than 18. Across mobility bands the number of symptoms remains broadly the same but the effect of symptoms increases.

However, a longitudinal examination of 13 respondents who answered symptom questions in 2013 and 2018 shows that not all symptoms persist from year to year and the number of symptoms tends to increase over time.

## Sleep

Respondents used a modified Global Sleep Assessment Questionnaire to describe their sleeping patterns, identifying if they are affected by 16 different sleep factors. The majority (80%) of respondents are affected by at least one sleep factor. Respondents affected by at least 6 factors (approximately one quarter) are shown to have a significantly lower wellbeing. There is no significant variation in sleep factors with mobility score, indicating that sleep factors are generally independent of mobility aids used.

The factor with the greatest effect, affecting nearly half of respondents is having difficulty falling asleep, staying asleep or feeling poorly rested in the morning. Needing the toilet in the night affects more than a third of respondents, and having repeated rhythmic jerks or twitches affects about a third of respondents.

93% of respondents usually or always sleep in a bed, and 1% of respondents usually or always sleep in a chair. The majority of the remainder of respondents indicate that they sometimes sleep in beds and sometimes sleep in chairs.

When reviewing the relationships between sleep and wellbeing it is not clear if a sleep factor affects wellbeing, or if wellbeing affects sleep, or if both sleep and wellbeing are affected by another factor. Those whose sleep is disturbed by feeling sad/anxious, by medications or by worries have a wellbeing which is significantly below average. Those whose sleep is not disturbed by feeling sad or anxious have a better wellbeing, but not significantly. This factor is similar to depression being the overall HSP factor with the greatest effect on wellbeing.

## Activities of Daily Living

Respondents selected the response which closely matched their situation for the six activities of daily living, as set out using the Katz Index of Independence in Activities of Daily Living (ADL). For each activity a respondent scores one point if they can undertake that activity independently and no points if they cannot.

Overall, a high score of six shows that the person is independent, and a low score of zero shows that the person is very dependent. Over half of respondents score six points and are fully independent, and that over one third score five points. The most common factor affecting people is their continence, their control of bladder or bowel.

Of the 84 of respondents who score 5 points, 74 are affected by the continence factor, with bathing (5 respondents) and dressing (four respondents) being the other two main factors. There are no clear patterns between the ADL factors and the use of mobility aids.

## Support Group Membership

Around 60% of respondents are members of a support group and 40% are not. The most common type of support groups identified were Facebook groups. Three key benefits people get from group membership are; getting to know other people with HSP, getting knowledge about HSP, and sharing stories. There is no difference in wellbeing between those that are members of support groups and those that are not.

The most common reasons given for not being in a support group were there not being a group near where respondents lived, not being aware of any support groups and not feeling the need to be a member of a support group.

There is no difference in wellbeing between those that are members of support groups and those that are not members of support groups

## Symptom Tracking

Half of respondents track their symptoms and half do not.

Almost all of those who do track symptoms described how they track those symptoms. The most common methods were; records produced by medical professionals, reviewing how things have changed from time to time and keeping a record/diary/log.

There is no difference in wellbeing between those that track their symptoms and those that do not.

## Wellbeing Conclusions

Several different factors have been shown to have large or significant effects on wellbeing, either positive or negative. Four of the symptoms with large wellbeing effects are related to mood; depression and stress overall, and sadness/anxiety and worries affecting sleep. Those who do not have depression or stress overall have a significantly higher wellbeing.

Many of the factors in these tables are not connected with mobility or other factors which are directly related to HSP. These factors may not form part of routine discussions with medical professionals which frequently focus on mobility, pain, continence and the other direct factors.

It is important to remember that it is possible to take action to improve some of these other factors. It is not necessary to accept, for example, that people are depressed, or cannot sleep well. Help or treatment is available for some factors, and getting such help/treatment may result in an improvement in wellbeing.



People should consult with a doctor or other medical professional to advise on the best course of action for any such action. Potential areas where changes could be made include:

- Decreasing: Depression, stress, anxiety, worries
- Lifestyle or other changes to improve sleep
- Reductions in pain
- Strength/balance training to reduce falls (or the impact of falls)
- Activity/exercise programme to slow down reductions in mobility

Wellbeing is not solely about health and examining your HSP progress and symptoms. Improvements in wellbeing can be made in other areas, including friendships, hobbies, learning new things, being kind and being mindful.

## Acknowledgements

Thank are due to all of the respondents who took time to respond to this survey, without these excellent answers this analysis would not be possible.

# Forthcoming Events

## Birmingham Meeting

Saturday April 6<sup>th</sup> midday – 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 March 30<sup>th</sup> 2pm onwards  
Prof Andrew Crosby from Exeter Uni will  
be updating us on his work.  
The Dartmoor Lodge Hotel  
Peartree Cross  
Ashburton  
Newton Abbot  
TQ13 7JW  
Call Ian Bennett on: 01202 849 391

## Milford Afternoon Tea South/South East

Saturday April 6<sup>th</sup> 3pm – 6pm  
The Clockhouse  
Milford  
GU8 5EZ  
Call Jane Bennett on: 020 8853 4089

## Colchester Meeting

Sunday, March 24<sup>th</sup> 2.30 - 5pm  
Feering Community Centre  
Feering  
Essex  
CO5 9QB  
We are hoping to be joined by HSP  
Chairman, Adam Lawrence  
Call Hilary Croydon: 01284 728 242  
[tohiti@btinternet.com](mailto:tohiti@btinternet.com)

## Stockport Meeting

Saturday 16<sup>th</sup> March 2pm – 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](mailto:Irena.pritchard@btinternet.com)

## HSP Support Group AGM

Saturday 13<sup>th</sup> July 2019 10 am – 4-30 pm  
Tally Ho Conference Centre  
Persore Road  
Birmingham  
B5 7RN

## New Members

We welcome the following new members:

Kathryn Lindsay  
Birmingham

Laura Kennedy  
Glasgow

Nick Callow  
Somerset

Rachel Ann Williams  
Clevedon

Rose Moore  
York

Scott Kennedy  
Glasgow

Mary Vickers  
Cambridge

Deborah Holt  
Peacehaven

Paul Goodwin  
Hyde

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	<a href="mailto:adam@idios.co.uk">adam@idios.co.uk</a>	07834 505 161
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	<a href="mailto:dave@vadcar.org.uk">dave@vadcar.org.uk</a>	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	<a href="mailto:john@jrmason.demon.co.uk">john@jrmason.demon.co.uk</a>	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:stephanyflower@gmail.com">stephanyflower@gmail.com</a>	01702 218 184
Ian Bennett – Membership Sec / Newsletter Editor 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	<a href="mailto:bravoechonovember@btinternet.com">bravoechonovember@btinternet.com</a>	01202 849 391
Jane Bennett – South / South East co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 8853 4089
Della Brookman – Trustee & Herts co-ordinator	<a href="mailto:della_brookman@msn.com">della_brookman@msn.com</a>	07710 637 941
Penny Cohen – Birmingham co-ordinator	<a href="mailto:pennycohen57@hotmail.com">pennycohen57@hotmail.com</a>	07818 288 738
June Masding – Birmingham co-ordinator	<a href="mailto:june_masding@hotmail.co.uk">june_masding@hotmail.co.uk</a>	01214 445 095
Mike Cain – Trustee & North West co-ordinator	<a href="mailto:michaelcain123456@yahoo.com">michaelcain123456@yahoo.com</a>	0161 456 7531
Irena Pritchard – North West co-ordinator	<a href="mailto:irena.pritchard@btinternet.com">irena.pritchard@btinternet.com</a>	01524 261 076
Hilary Croydon - Colchester co-ordinator	<a href="mailto:tohiti@btinternet.com">tohiti@btinternet.com</a>	01284 728 242
Barbara Jones – Norwich co-ordinator		01603 423 267
Liz Redmond - Neurogenetics Nurse based at The National Hospital of Neurology & Neurosurgery	<a href="mailto:Redmond.liz@uclh.nhs.uk">Redmond.liz@uclh.nhs.uk</a>	02034 484 487