

HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 51 – March 2021

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

Vicki, the Queen Bee of HSP



2020 was my first year of beekeeping!
And it has been really magical! My
journey to being a beekeeper and
particularly a beekeeper with a
disability has been a peculiar and very
lucky journey!

I had been interested in beekeeping
for a few years but had been put off by
what I had read and been told by local

conventional beekeepers about the
work involved, the burden of the
responsibility, the heavy lifting and
qualifications one is expected to
achieve to be a proper beekeeper.
However, my opinion completely
changed when I attended a 2-day
course by Dr leo Sharashkin about
natural beekeeping with a Layens

hive. Most hives in the UK are made up of boxes which stack on top of each other, a vertical hive, but Dr Leo was promoting a horizontal hive, the Layens hive – like a chest with a lid! Dr Leo said this type of beekeeping was largely about giving bees a home and just letting them live with minimal interference. Bees do not like having their home disturbed! Also there is far less for the beekeeper to do and certainly very little lifting 1. because you don't go into the hive very often - perhaps a few times a year and 2. the most you have to lift is the lid and the individual frame (as in my photo).

I was totally converted by Dr Leo and with great excitement bought a Layens hive in February to keep in my garden. It's not a huge garden and I live in a town but the course gave me the confidence to give this natural beekeeping a go! I ordered some bees from a local beekeeper and was looking forward to getting the hive set up in the early summer of 2020. Then lockdown happened! The business selling the bees ceased selling bees for 2020 and was most disappointed. An empty beehive sat outside my backdoor for a few weeks until... one sunny day in April I saw bees going in and out of my hive! I was so excited I shouted to my husband that we needed to get the hive in position in the garden as the scout bees were checking it out to move in! And on 30 May 2020, after considerable interest from scout bees, a whole swarm flew in at around 11am, like a golden cloud at the bottom of my garden. I was so overwhelmed - it felt like a lockdown miracle!

That colony of bees has thrived all year. They have built comb and honey and I have been lucky enough to see her majesty the queen bee! I haven't removed any honey as one of the principles of natural beekeeping is not to feed the bees sugar but to leave them with plenty of their honey especially in their first year and then, in the following year, I can enjoy any surplus honey. I'm really looking forward to that! I am a happy beekeeper with happy bees I reckon!

I would very much recommend beekeeping with a Layens hive to anyone and especially for anyone who cannot do heavy lifting. I only had one sting and I felt pretty guilty about that! Most days I sit at the hive entrance with my cup of coffee amongst the bees watching them flying to and from the hive and watching them on the lavender, brambles and tree blossoms. It is such a joy! There is so little work and this type of beekeeping is not a worry or burden. In fact, the more you just leave the bees to get on being bees the better! I have documented my journey with natural beekeeping with a Layens hive on You Tube so, if this article has interested you, please look up 'Bee Lady Vicki' and find out more. I would be thrilled if others could enjoy the experience I've had and have the joy and satisfaction of protecting threatened bee populations in the uk – even in a modest urban garden! Best wishes all for 2021!

Vicki Garratt

Chairman's Column

Happy New Year Everyone! – One positive of the groups new website is that it has become much easier for people to join up and become members, so I'd also like to say welcome to anyone who has joined the group recently. Hopefully you're enjoying our friendly supportive community, and I'd be happy to hear from anyone with ideas for things we could do differently. This is another column from me with several different things in it, so I'm using sub-headings again so that you can easily see where things are.

Coronavirus Vaccine

In the news recently there have been reports that those with learning disabilities are more likely to die from Covid-19. People who have complex HSP which includes cognitive problems (this might also be called intellectual disability or learning difficulties) are more likely to be considered extremely vulnerable. Depending on exact circumstances these people are likely to be in one of the higher groups (group 4) for Covid-19 vaccination, particularly if those cognitive impairments are advanced or neurological problems are complex. If this applies to you, please contact your GP if you have not received an invitation to be vaccinated.

Those people who have more advanced HSP without cognitive problems will meet the criteria for underlying health conditions (group 6), and they should watch out for vaccination invitations soon. Those people who have mild HSP probably have a similar risk profile to people of the same age, but could still be classified under group 6 as they have a chronic neurological condition. If you are not sure then please discuss with your neurologist or your GP.

There have also been a few questions floating around from people querying if having HSP should be a cause for concern when having one of the vaccines for Covid-19. We are not aware of any such concerns, and I advise anyone to discuss any concerns with their GP before having their vaccination. The overwhelming body of evidence shows the available vaccines are safe and effective, with remarkably few side effects other than a mild local reaction (arm soreness at injection site) and mild general symptoms (e.g. slight fever or tiredness) in about 10-20% of cases. These typically only last a day or so. So the risks from catching coronavirus are far greater than any risks from vaccination.

Potential Group Name Change

You may remember the last NewsLink where I mentioned options for changing the group name. The three choices are: HSP UK, HSP Foundation and HSP Group. We will ask for members to vote on this at the AGM, and will include an option for leaving the name as it is.

Meetings Update

Given that (as I write) we are in middle of our third England lockdown, we have taken the decision not to have any face-to-face meetings before May 1st. We will keep the situation under review as the lockdown restrictions lift, and we will decide when to restart face-to-face meetings, and make a similar decision about the AGM.

In the meantime, I encourage you all to take part in one of our Zoom meetings. Our excellent team of meeting organisers have been running various meetings through the Autumn, and several are getting booked in over the next month or two. These are really good meetings, and they save all the effort of travelling. Please reach out if you are having technology problems. You can read up about recent and upcoming meetings elsewhere in this newslink!

As many of you know, we recently formed a committee of meeting organisers to help share knowledge and ideas between meetings, and to make it less daunting to set up a new meeting. Since the committee has started, I am pleased to say that we have a couple of people who are looking to start up meetings in their areas. However, we are looking for a new chair for this committee - Hilary Croydon is stepping down as she has many other commitments which she needs to balance. Hilary has done an excellent job with Jane as the committee's first chair, and I thank her for that. Please drop me a line if you are a friendly, chatty person and fancy helping the friendly committee. As committee chair, you don't have to organise group meetings yourself, you can just act to help others organise their meetings.

2021 Award Nominations

We will be running our two awards at the AGM this year, and we would welcome any nominations for these. There is a Fundraising award and a Raising Awareness of HSP award. Please drop me or one of the trustees a line with any nominations.

YouTube Channel Updates

Our YouTube channel now has a short summary version of the AGM, which gives the key points. This has been made by Yuqian Ye, who recently offered her help to the group. You may also be interested to see the new additions to the "People with HSP" playlist on the channel. We are now working on videos of some of the Q&A from the presentations last summer. Here is a link to the channel: <https://www.youtube.com/channel/UckxTfcl4tKYNMysgzVumpWA>

Policy Updates

We are in the process of updating some of the group's policies, and these are now beginning to feature on the website. You can find updated policies for expenses, use of funds and risk, and a new code of conduct. (<https://hspgroup.org/privacy-policy/>).

Want to Help The Group?

Please remember our website page with help we would like (<https://hspgroup.org/want-to-be-able-to-help-the-group/>). If you happen to talk to someone who might have the right skills, drop me a line or point them at our website. Helping the group is good for them and good for us!

Fundraising Reminders

Please remember that you can easily raise money for the group when doing your shopping online, at no additional cost. There are two ways of doing this. You can use Easyfundraising.co.uk (<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/?invite=SBBB4F&referral-campaign=s2s>) or Amazon Smile (<https://smile.amazon.co.uk/ch/1181539-0>).

Another option (through JustGiving) is to use Ziffit to sell your unwanted books, CDs, DVDs and games, donating the money to the group (<https://www.ziffit.com/en-gb/basket?charityResourceId=5d32af48-3cf7-11e3-80f9-00237d37086c>).

My Annual Survey

In the last issue, I let you know about my annual survey, and the results are now available. You can read a summary at the end of this newslink, or a full version on my blog. Thank you to anyone who has taken part. Here is a link to the page on my blog:

<https://hspjourney.blogspot.com/2021/02/2020-survey-results.html>

Adam Lawrence

Editor's Column



I've mentioned my grandson Bennett in previous issues so I thought I'd start this article with a picture of the two of us. How can that little face not cheer you up during these turbulent times and I'm referring to the one on the left. I can't believe that Bennett was one last month, it's amazing how the time flies, even when in lockdown. I've been very lucky because he lives only five houses down the road and we've been allowed to form a bubble with his family (my daughter) and help with babysitting duties so that mum and dad can work from home. His arrival back in January last year, and more recently, his cheeky little grin and lovely personality have been a big factor in making 2020 a good year, despite the very unusual circumstances.

My household and baby Bennett's household regularly venture out for local walks and I use my wheelchair to keep up. This has been the fun part of my regular daily exercise where I go out on my chair and complete at least two miles. I try to include some local hills as these get me puffing and panting and get the heart working a little harder. I was given a smart watch for Christmas and I soon noticed that each propulsion of the wheelchair wheels registered as a step on my watch. I've set a daily target of 4000 steps and it's only when the weather is awful that I don't achieve this. I see another half marathon coming on and maybe I can raise a few pennies for our cause.

I continue to try to stay on top of my garden but the cold spell we had at the beginning of this month (February) put outside chores on hold for a

while. However, as I write this, the weather has turned very mild, I have daffodils in full flower and a pond full of frog's spawn. These are all sure signs that the winter is nearly over and from now on, outdoor life will just get better and better. Bring it on!

I'm still loving my duties hosting a show on local radio where I play music from Dorset and Hampshire. If you're ever twiddling your thumbs at 8pm on a Friday evening, ask Alexa or whichever equivalent you may have, to play Forest FM, and hopefully I won't bore you too much. If you let me know you're listening in, I'll give you a shout out.

When I wrote my column for the last newsletter in October last year it seemed, that we'd finally got on top of this awful covid situation. Never in my craziest of dreams did I anticipate that it was all suddenly going to get much worse and that as you read this, we've all recently been through lockdown number three. You'll notice by reading about some of the activities that our members have got up to, that many of you have been, and are coping well with circumstances. However, for anyone who's feeling a little low or anxious, please remember that I'm always on the end of the telephone.

A very good friend of mine who has MS pointed me in the direction of the following link <https://mstrust.org.uk/a-z/w> It's an A to Z of MS created by the MS Trust but because of many similarities between MS and HSP, much of this information applies to us. I'm sure some of you will find this of interest and maybe we should create as A to Z of HSP.

You'll notice at the very end of this edition that there is a cartoon. Wilma's Wheels will be a recurring cartoon in the newsletter and Kevin Mills, (one of our members), is the cartoonist.

The HSP support Group has recently started using Zoom to conduct meetings and you'll read more about this later in this Newslink, but this has been great for keeping in touch with one another and raising spirits.

I hope I get to see some of you in person in the not-too-distant future, but if not, I'll hopefully see you on zoom. Look after yourselves, stay safe and keep in touch.

Ian Bennett

Turning a Negative into a Positive with HSP Zooming

Unfortunately, it's been well over a year now since any of our members have had the opportunity to meet up at one of the various regional meetings that the Group now organizes. This of course is due to the COVID-19 pandemic and the consequential rules and restrictions that we have had to make to protect our members and help prevent the virus spreading. At a recent trustee meeting we took the decision to continue with this policy until May 1st when we'll then decide whether or not it's safe to resume physical meetings. This was a hard decision to make because we all appreciate how important our physical meetings are but the health and welfare of our members has to be our priority.

However, during the course of the pandemic and the three lockdowns, we have now discovered the world of virtual meetings. Thanks to the Zoom platform, we have already conducted several on-line meetings and you'll read about some of these later in this Newslink. We also conducted last year's AGM on zoom and our fears of a low turnout were proven to be unnecessary as we probably had more members attending an AGM than we've ever had before. I even hosted a zoom meeting on Christmas day for anyone who was alone and possibly feeling a little low and this was attended by five members.

Zoom meetings have proven to be a great way of getting members together and socializing or chatting about their HSP issues. One big advantage that we've noticed with zoom is that there are some members who find it very difficult to attend a physical meeting because of their mobility problems, but using their phone, tablet or PC to attend a meeting from the comfort of their home is easy for them and allows them to participate.

We're aware that some people may be afraid or unfamiliar with zoom and it can definitely seem a little bewildering at first but it's really very straightforward once you get used to it.

If any members would like to join us at a future zoom meeting but are baffled by the technology, we're always here to help and I'd suggest that you either contact Adam or myself. Alternatively, if you're fortunate enough to have any clever youngsters in your family, just ask them for assistance, they'll find it easy.

We can't wait for the Covid situation to end, giving us the opportunity to resume our very important physical get togethers. However, Zoom meetings have proven to be such a success that we'll definitely continue to conduct them in addition to the physical meetings and who knows, we may even try to be very clever and combine the two.

I hope to see many of you at future meetings, both in person or on Zoom.

Ian Bennett

New Meeting Organisers

The HSP Support Group are always after volunteers to organize regional meetings. I'm delighted to be able to tell you that three members have recently offered to help us with this. Cath Ward, Joseph Mills and Kevin Mills have all said they'll help get hsp'rs together in their local areas. Cath lives in Sheffield, Joseph is in Scotland and Kevin is in South Wales so be prepared to be advised of new meetings in these locations. The three of them are all getting used to using Zoom and I'm sure they'll be hosting both virtual and face to face meetings.

I can't thank Cath, Joseph and Kevin enough for taking on this very important role. There are many areas of the UK where HSP meetings don't currently take place so if this is of interest to you, please get in touch with any trustee. We'll give you all the help you need and we now have a very comprehensive guide that gives you loads of tips and guidance on setting up and hosting a regional meeting.

Ian Bennett

Fundraising News

Please read this!

Since I publicised [Easyfundraising.org.uk](https://www.easyfundraising.org.uk) at our 2019 AGM, we now have 56 individuals raising funds for us using this facility and we have raised just over £700.00 to date including £36.05 in the last 30 days.

We have nearly 400 members, and no end of friends, so we should easily be able to attract many more than 53 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 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 56 people who have already signed up to this great facility.

We are now 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. Please bear this in mind when doing your Christmas shopping.

I'd like to end this brief article on fundraising with some very good news. Many charities

are struggling to raise funds during the lockdowns and other restrictions associated with the Covid pandemic and although the HSP Support Group have also been affected by this, we've managed to buck the trend a little and have raised £7466 since May 1st last year. I'd like to thank everyone who has generously donated during these difficult times.

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 £750. 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.

Members' Letters

Brooke's Bike Journey ultimately to an Electric Recumbent trike, one day !!!

My journey on an electric bike started I think possibly nine or ten years ago. I saw an electric version of a petrol powered Solex bicycle whilst out in France. Having previously owned an original petrol Solex I was curious to find out more.

On my return to the UK I researched the cost of the electric powered Solex which seemed ideal as the model I was interested in was a folding option. However, I found the electric Solex to be out of my league! On researching further I found a suitable alternative folding electric bike.

With the help of a grant from the HSP support group I was able to purchase the folding electric bike which I was able to bring along

and demonstrate at one of Jane & Michael's afternoon teas at Milford.

My electric bike was my way back to cycling. I had always enjoyed getting out and about on my bike, often off road through our local woods and country lanes. We had cycled a lot as a family with the children when they were younger along routes like the cuckoo trail which uses disused railway lines.

Over the years it has become more & more difficult to ride a conventional bike due predominantly to my left foot slipping off the pedal. I had been fortunate to have tested some Shimano pedals with steel studs whilst at Centre Parc which helped to prevent my feet slipping, so I set about changing them on my bike.

My cycling opportunities diminished until recently when a group of friends formed a new cycling group as a social way to meet up and take exercise. There are between ten and twenty in the group, male and female, experienced cyclists and those who are new to cycling. So for our first few outings we met in East Grinstead to cycle part of the Forest Way. The Covid restrictions at that time allowed us to enjoy refreshment in a pub garden as long as we ordered and paid for our food and drinks via an app.



We had several more cycling trips with the pub garden lunch mid-way as this was now the norm and the weather was good. However, on these trips it has become

apparent that I am no longer able to pedal assist my electric bike. I literally ride it like a moped as it has a twist throttle, which is fine as long as long as gradient isn't too severe!

At a new location Bewl Water a reservoir near Lamberhurst, Kent we all found it quite a challenging route. Just before our lunch stop we encountered a very steep uphill unmade tree root obstacle track, a small minority were able to cycle up, the rest had to push their bikes or for me I had to dismount and be supported by my wife one side and a friend the other. My bike was taken up to the summit by one of the others.

As the ground around the reservoir was very uneven and bumpy my left foot was a problem constantly sliding off the pedal This is where we revisit in my earlier story of me telling you about the steel studs on pedals which on this occasion wreaked havoc on the back of my left lower calf, so much so one of my lovely friends had to wipe the blood off my wounds with a tissue and water.

After another great alfresco pub lunch we set off to finish the trail of Bewl water however, my electric bike ran out of juice! I was going up another unmade track when I cried out "HELP I've lost power and can't ride"! Again friends to the rescue, they got me and my bike to summit of the hill, I was then able to coast downhill but the final stretch was a long flat section across the dam! This is where two friends – Dave and Cheré became absolute heroes, whilst cycling their bikes they pushed me with one arm each on my back all the way across the dam and back to our cars, which was probably half to three quarters of a mile what a feat!

My days were numbered riding a conventional two wheeled bike as lovely as it was getting out in the fresh air with the gang I wasn't actually getting any exercise. Researching further and not giving up I found London Recumbents in Dulwich Park London. I made an appointment to go and have a look at a trike. After some quite lengthy adjustments on the bikes used for demonstrations together with fitting different pedals with foot clips & elastic straps to hold

the feet I was able to test ride trike round the park.

This has led to me being able to use a trike through an organization called Wheels for Wellbeing, (*Wheels). I have now cycled several times around the famous velodrome at Herne Hill South London, and from Dulwich Park & Ladywell in South London to Greenwich & The Cutty Sark. Before the third lockdown I was cycling twice a week with (*Wheels,). I am going to be able to have my first ride at Herne Hill Velodrome on Friday 15 January first ride since before Christmas. It's really great to be able to get some Exercise and be out in the fresh air again.

I strongly recommend anyone from the HSP group living in South London or the surrounding areas to check out Wheels for Wellbeing. They have every type of bike you can imagine including hand bikes, even a bike that your personal wheelchair can go on a platform in front with a carer pedalling the bike behind.

For full information visit:

<https://wheelsforwellbeing.org.uk/>

Stay healthy & safe everyone

All the best

Brooke

My Garden is Special!

During 'Lockdown' I have been watching the number and species of birds that frequent my garden. In order to encourage them and help them during these cold winter months, I put out a variety of food for a range of species, Eg seed, peanuts, lard, etc. They have a number of adaptations for finding food, so the offering has to match their specific adaptation. These adaptations are often related to their beak shapes and sizes and how they feed, eg are they ground feeders or can they perch on a feeding station?

Most garden birds fall into two categories of feeding. These are:

Seed feeders, like Blue, Great, Coal and Long-tailed tits and some finches eg Greenfinch, hang from seed holders.



A blue tit in Gary's garden

Ground (flat surfaces) feeders such as Chaffinches, Robins, Blackbirds, Song Thrushes, that consume from bird-tables, or the ground where they are at risk of predation.

I also spread lard onto bark of trees or shrubs. I then cover this with seeds. This enables the birds to find their food, particularly those that frequently searching in confined places. These birds counted towards the RSPB Garden Birdwatch census over the last weekend of January.

Soon, what will grab my attention more, as February turns to March is the 'teacher-teacher' call of Great tits which will echo in my garden and the near-by woodland. Summer visitors will to come like Chiffchaffs, which are often the first arrivals; sometimes in early March. Then frequently Blackcaps follow, both with insectivorous beaks. They often over-winter in our gardens. This is before our countryside is full of other summer migrants.

I have been largely staying at home obviously to comply, but have occasionally ventured out on my mobility scooter. Not for physical exercise, as my legs won't move, but to obtain exercise for the 'Mind'. Kelsey Park, in Beckenham, has all-weather paths, so there is no chance of my small wheels becoming stuck in any mud. It has a large lake teeming with birdlife, mainly ducks, also Cormorants and an alien from China, beautiful Mandarin ducks. Just getting out to this park, via an accessible taxi, was a real relief.

Here in my garden and local park, I could take in nature's promise!

Gary Cliffe

Hello fellow members, I have been a member for a couple of years now and I was going to host a S.Wales members meeting, but then Covid came along.

I was in touch with the Committee and was invited to a committee zoom meeting which I attended on Tues 5th Jan. At first I thought it may be a bit full on so I wasn't too sure, but I was made to feel comfortable from the start and soon realised that it was the perfect way for us members to connect until we can get back to face to face meetings. I now intend to host my own zoom meeting for members in the S. Wales area and any members will be given joining instructions.

Hope to see you all there.

I have also suffered from 'bad Cloneus' or 'jumping feet' as I call it, and it was really affecting my life and stopping me from sleeping. I suffered with it for years before someone told me that they also suffered with it and told me that they slept with their legs and feet covered with a 'weighted blanket'.

I have tried one of these blankets and I really think that it combats the condition really well, but I have also been taking CBD oil as well, so I don't know if it's the blanket, the CBD oil or a combination of both, either way I can relax and sleep a lot better.

Best Regards

Kevin Mills

Milford Zoom Meeting

On November 8th, not wanting to miss out on a celebration, fourteen of us raised a glass, cup or mug in honour of twenty years of the Milford meetings. When face to face meetings return, hopefully in 2021, we'll celebrate together.

Only those members that keep in email contact were invited to the meeting, with eleven confirming before the date. I send my apologies to Penny and Lorraine for not inviting them as they were at our first meeting.

We would have enjoyed seeing more people, but having a limited number, enabled

everyone to chat easily for 75 minutes. Although the emphasis was on seeing each other and catching up, discussion topics agreed before the meeting included:

If, and how, HSP is affected by medical treatments, and, perhaps, the reverse

The AGM

Effects of lockdown

Living with our disability.

During discussions, the topic of speakers came up. Several suggestions were made, including a couple of requests for previous speakers to be invited again. If we do return to meetings, all I have to do is send some emails!!

A couple were saying that they don't attend the November meeting in Milford due to travelling in the dark. A consideration is to have a Zoom meeting, for those that couldn't attend, with some who did, perhaps a week later. This is certainly worth thinking about.

Scotland Zoom Meeting 6/12/2020

Those Present

Mike Cain
Lynn Ross Mills and Joseph
Andy Anderson and Gregor
Graeme Anderson
Karen Begley and Gregor
Audrey Kennedy and Scott
Dorothy Stuart
David Hood
Helen Wolfe

Introduction

I had allowed two minutes each but we soon forgot about that and spent most of the meet sharing experiences and seeing the different services available in Scotland.

There is a vast range of age at onset and having a relative showing no symptoms did not mean that relative would not have a later onset.

What was common was a lack of information, or knowledge of Hereditary Spastic Paraplegia

because HSP is also synonymous with ‘Highly Sensitive Person’ which is also listed by NHS.

The reason for this meeting was because Mark Mills came down to Stockport in his wheelchair, three trains and stayed overnight to suggest we had a Scottish meeting. Stirling was chosen for a physical meeting as it was about equal travelling distance for those who responded via facebook. Covid took over and we eventually gave up and resorted to Zoom for the timebeing.

It was notable how many young people were there and how some were heavily involved in sport – basketball, rugby, curling, tennis with the positive idea that you need to think how you want to do something.

We talked about the different services available and whether they should be free if they are provided by the same NHS.

We talked about how some knowledge is better than elsewhere and shared some doctors/hospitals.

People shared their gene (SPG) . Professor Zosia (pronounced Zosha) Miedzybrodzka is based in Aberdeen University and is the Genetics lead in Scotland , and Dundee is a centre of Knowledge of HSP (though it is not widely known). Zosia has said that Genes differ as you travel from North to South Scotland.

The centres of knowledge in England are The National Hospital for Neurology and Neurosurgery (commonly known as Queens Square London) and Royal Hallamshire Hospital Sheffield. Direct trains from Aberdeen, Dundee, Edinburgh and Glasgow go twice daily to Sheffield and direct trains run frequently from Glasgow Central to Euston (near Queens Sq) There is also a direct frequent service from Edinburgh to London Kings Cross though engineering work at present means the trains do not reach London, and the new trains are not wheelchair comfortable.

The Scottish Government, through Health Boards, has funds available for residents of Scotland to travel to centres of excellence. So

far it is unused. I am to find out more explanation of how to use it.

We discussed the availability of trainers for use with orthotics as well as the cost of frequent replacements with both wear and tear as well as growth. Some that Ive been reccomended a Nike Flyease and they do seem easy to get on/off with Velcro fasteners, but they are expensive as well as not being widely available even on the Nike site. Others were mentioned such as trainers with steel toecaps

Locations

For the time being we will stick with Zoom and communicate via WhatsApp and someone there agreed to act as ‘keeper’ of the group numbers. People used messenger to send their phone numbers to Karen and future people from Scotland might like to send their numbers to Karen and keep updated

Apparently Whats App can be downloaded onto a desktop PC. Gregor made it sound simple so it works even without a smartphone and can probably use your landline to show a message on screen.

Contact with CPG in Edinburgh

At present they are meeting online and I am happy to continue as the HSP group through Genetics Alliance

If the meetings are real, they may be in Edinburgh but also in Aberdeen and Dundee where they have been in the past.

There is also an election next year so we may have a different Scottish Government

Places of Treatment

Dundee Nine Elms Hospital / Dundee University

Glasgow, QE Hospital, Dr Maria Ferugia

Ann Rowling Clinic Edinburgh University/ Edinburgh RI

Health Boards

Any others?

Dr Campbell, Dr Jollins, Aberdeen,

Professor Pills Glasgow Neurology
 Craig Albert Cumbernauld (for children)
 Enablement Scotland

Membership of hspgroup.org

People were asked to join via the website
 hspgroup.org

Next meetings

A following Zoom meeting will be held in two months time and a physical meeting is planned for May 2021

A date was not set

I have transferrewd my booking at hotel in Stirling and Glenrothes to May 29/30/31/2021. (it was shunted a few times in 2020) , This is subject to Covid changes.

We should be able to set local meetings up, initially by Zoom and include others.

Mike Cain

First Ashburton Zoom meeting 15/11/2020

The First Ashburton zoom meeting was advertised in the newsletter and reminders were sent out by email to members in the south west.

The meeting started at 2-30 pm and at one point there were 25 people in attendance. About half of those attending were regular Ashburton attendees and the remainder were from around the country including five other meeting organisers who were their to gain zoom experience.

The meeting commenced with a brief welcome to all and a summary of the meetings activities.

I gave a presentation on Flying Scholarships for disabled people and the effect it has on the lives of those who participate, with a particular focus on those with HSP who've been through this wonderful experience. This presentation lasted about 40 minutes and there were a few questions at the end.

A five-minute break was taken for people to get a drink or use the bathroom.

Following the break, I held a general knowledge quiz with 40 questions including a few questions relating to HSP and Ashburton. The quiz took about 40 minutes and fun was had adding scores up at the end and congratulating the winner.

After the quiz we spent about 20 minutes chatting amongst ourselves. A couple of interesting mobility devises were discussed including off road mobility scooters and electric trikes. The meeting had been running for an hour and forty-five minutes when we said our goodbyes.

Ian Bennett

Midlands Zoom Meeting 31/1/2021

We shared a lovely Zoom today with 12 UK members, one completely new to the Support Group, some from different regions, and several of our regular members too.

Everyone was happy to introduce themselves, and it was really nice to share and exchange our own personal HSP journeys, all similar in many ways, and so different in others.

It was uplifting to hear some really positive views and experiences about wheelchairs that our members used. One member used a lightweight chair that could either be powered by hand-cycling, or by battery, made by Team Hybrid, in Portsmouth.

Do have a browse, here is the link:

<https://www.teamhybrid.co.uk>

We talked about how exercise is so very much needed for anyone with HSP – “Use it or lose it” has been heard by us all, and of course with restrictions in the lockdown, and having just had lots of Christmas fayre, is even more important.

One member said how much he enjoyed doing Aerobics at home in his wheelchair! He suggested we looked at YouTube, putting “Seated Aerobics” into the search. You’ll find

LOADS of fun and not-too difficult exercises of all different styles and strengths, and for all ages too, so you will be able to choose one to suit your own personal needs.

It was lovely to have a free, open and warm natter together today - we couldn't find the 'mute' button but found it really wasn't needed. We just asked everyone firstly to listen to the news that we had to share, and when everyone had introduced themselves, raise a hand if they wanted to share something and worked really well for us all.

Our next zoom chat will be on Sunday 18th April at 3pm, please look out for your email from John Mason, or on the HSP Website, or Facebook HSP UK.

If you are interested =, please contact either of us for the link details:

Penny Cohen - pennycohen57@hotmail.com
Mob: 07818 288738

June Masding – june_masding@hotmail.co.uk
Mob: 07500 584681

Penny Cohen & June Masding

Forthcoming Events

Stockport Meeting

07/03/2021 2pm – 5pm

Online using zoom

michaelcain123456@yahoo.com for details

A Meeting for all members

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

14/03/2021 2-30pm, online using Zoom

Contact Ian Bennett: 01202 849 391 or bravoechoonovember@btinternet.com for info

Wales Meeting

21/03/2021 2pm onwards

Online using the Zoom platform

Contact Kevin Mills for info: 01874 622 727

Hitchin Get Together

10/04/2021 – 3pm -4-30pm

Online using the Zoom platform

For details contact Della Brookman

della_brookman@msn.com or 07710637941

Milford Meeting

17/04/2021 3pm – 6pm

Online using the Zoom platform

Contact Jane Bennett : 02088 534 089

Virtual Ashburton Meeting

24/04/2021 2pm – 5pm

In the comfort of your own home

Online using the Zoom platform

Contact Ian Bennett : 01202 849 391

Malton Meeting

11/04/2021 2pm – 5pm

Online using zoom

michaelcain123456@yahoo.com for details

Newcastle Meeting

25/04/2021 2pm – 5pm

Online using zoom

michaelcain123456@yahoo.com for details

New Members

We welcome the following new members:

Hayley Kavanagh
Fleet, Hants

Amanda Fallaize
Winsford, Cheshire

Veronica Grima
Salford

Paul Young
Oxford

If you are interested in contacting any of the above new members, please contact our membership secretary, Mitesh Patel (miteshpatel59@hotmail.com)

The results of Adam Lawrence's eighth survey, launched October 2020

Full results for all surveys, including this one, are published in Adam's blog:

<https://hspjourney.blogspot.com/2021/02/2020-survey-results.html>

There were 317 respondents who completed this 2020 survey, predominantly from the UK, Brasil and USA, as shown. I thank all the respondents in many countries who took time to respond to this survey, without these excellent answers this analysis would not be possible. I also thank those individuals in different HSP groups and other places who assisted with the translations of the survey.

Location	Respondents	Percentage
UK	69	22%
Brasil	67	21%
USA	51	16%
France	39	12%
Netherlands	21	7%
Canada	17	5%
Australia	16	5%
Other Europe	32	10%
Rest of world	5	2%

A brief analysis shows that 170 people who completed this survey had also completed at least one of my previous surveys, representing about 54% of respondents, the proportion is increased from 2019. There are ten people who have completed six or more of my eight surveys.

1) Wellbeing

In order to assess the wellbeing of people with HSP, respondents completed the Warwick-Edinburgh Mental Well-being scale (WEMWBS). The total score is higher for those with a better wellbeing. The average score across England and Scotland populations is 51-52 with most scoring between 41 and 59.

There were 308 respondents who answered this question, with the average wellbeing score of 42.9, which is lower than the average scores of 47.4 in 2019 and 45.9 in 2017 and 2018. If the average wellbeing score is within +/-3 points of the overall average, then the effect is not significant. If an average is more than 5 points from the overall average, then this is likely to be significant, particularly for groups of over 50 respondents.

Wellbeing scores that could be significantly different from the average have been shaded yellow or light green, and those that are likely to be significantly different from the average are shaded orange and green.

It is relevant to note that this years' average score is approximately five points lower than last years' average score, potentially indicating that wellbeing between 2019 and 2020 has dropped significantly. One potential explanation for lower wellbeing this year is the effect of Coronavirus on people around the world, with people having answered these questions October to December 2020.

The wellbeing score for respondents from the UK is 42.4, slightly below the overall average of 42.9. Those who have SPG4 have an average wellbeing of 44.8, slightly above the overall HSP average. Those with SPG7 have a lower wellbeing score of 37.9, 5 points below the average and consistent with results from 2019. There are insufficient people with SPG11 in this survey to assess if having SPG11 is a factor in peoples wellbeing.

2) Mobility Analysis

Just over half of respondents use walking sticks/poles/crutches/ canes, two fifths use wheelchairs/mobility scooters and just over a quarter use 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 7 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.

Mobility Aids Used - Summary:	Respondents	Percentage
Using sticks/poles/crutches/canes	161	51%
Using Wheelchair/Mobility Scooter	128	40%
Using Walking Frame/Rollator	88	28%
Using Orthotics/AFO/Insoles	92	29%
Using FES	11	3%

The results also allow the distribution of respondents within a scale of mobility to be understood. I have devised an “HSP mobility score” which then allows me to cross-reference mobility against the other questions in the questionnaire. The definition of the HSP mobility score is;

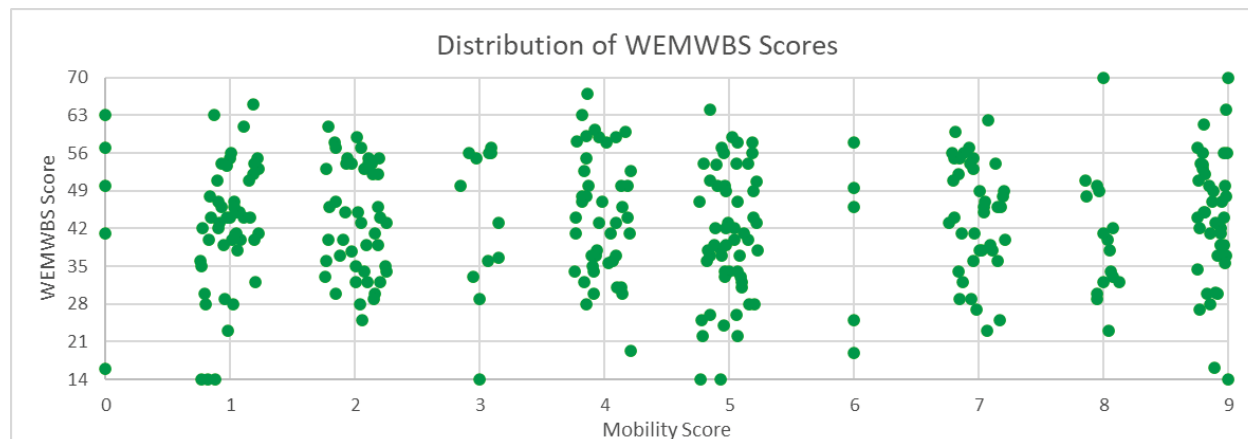
0. No mobility effects
1. Can walk without aids but some effects
2. Orthotics/AFO/FES and/or Sticks/Poles/Crutches/Canes some of the time
3. Sticks/Poles/Crutches/Canes and Frame/Chair some of the time
4. Sticks/Poles/Crutches/Canes most of the time
5. Sticks/Poles/Crutches/Canes all of the time
6. Rollator/Walking frame most of the time
7. Rollator/Walking frame all of the time
8. Wheelchair/Mobility scooter most of the time
9. Wheelchair/Mobility scooter all of the time

The results are simplified into five broader groups;

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score	Wellbeing
Those without aids	54	17%	0-1	43.7
Those who use mobility aids some of the time	59	19%	2-3	42.4
Those who use sticks most/all of the time	101	32%	4-5	42.8
Those who use frames most/all of the time	44	14%	6-7	44.0
Those who use chairs most/all of the time	58	18%	8-9	42.2

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 of numbers of people between bands.

The wellbeing scores do not vary significantly across types of walking aid being used. The distribution of wellbeing scores is shown for all respondents in the following figure, split by mobility score.



3) Needs

Questions were asked to identify the needs of people with HSP, based on a list of needs derived from observing people's stories and concerns over time, and the experiences of people with HSP from different areas. The list of needs was split into five topics. In the questionnaire, respondents were asked to select their top five needs in each category.

To rank the different needs into an overall list, the total number of votes for each need has been weighted by the rank, so the total score is:

$$(\text{Top Rank} * 5) + (2^{\text{nd}} \text{ Rank} * 4) + (3^{\text{rd}} \text{ Rank} * 3) + (4^{\text{th}} \text{ Rank} * 2) + (5^{\text{th}} \text{ Rank}).$$

The results were also reviewed, and any duplicate answers given by people were deleted, such that for any one individual a choice is counted once in the overall score. Some people chose to choose five different needs, whereas others chose fewer than five needs or skipped some topics. Between 300 and 312 respondents gave answers for each topic.

For each topic, a table reports the number of people choosing the need as their most important need (1st rank), the total number of people choosing the need in any rank including first rank (total votes), the weighted score (score), and the weighted score expressed as a percentage of the highest scoring need (percent). The background of the percent column has been shaded to show the relative importance of each, with the more important needs being shaded darker green. The top five needs for UK respondents have been shown in bold. Similar scoring needs are grouped using light shading.

Living with HSP

This topic included 20 needs.

Living with HSP Needs	1 st Rank	Total Votes	Score	Percent
Stretches and exercises that help	129	211	907	100%
Information on appropriate physical activities to take part in	34	135	500	55%
Information on tailoring physical activities to suit HSP	22	109	367	40%
Information on how best to walk	19	104	324	36%
Information on living with HSP & other long-term conditions	30	92	305	34%
Understanding if changes/new symptoms are to do with HSP	15	86	246	27%
Information on staying healthy with reduced mobility	12	86	242	27%
Information on how to select mobility aids	7	88	242	27%
Information on getting up from falls	8	70	199	22%
Information on how participation levels may change over time	9	67	185	20%
Information on types of modifications around the home	6	60	143	16%
Understanding when to review/change treatments	5	54	138	15%
Information on how dietary choices can influence HSP	3	57	136	15%
Information on how to use mobility aids	3	42	96	11%
Information on when to change mobility aids	4	34	92	10%
Information on when you might need home modifications	1	41	95	10%
Information on best practice using the toilet	1	37	79	9%
Information on dietary supplements and their effects on HSP	1	32	67	7%
Information on driving with HSP	1	29	61	7%
Information on reviewing/changing modifications around the home	1	17	47	5%

Stretches and exercises that help is the clear top need in this topic, with 41% of respondents identifying it as their top need. The second need is information on appropriate physical activities to take part in. The remaining needs are in fairly distinct groups, with percentages in the ranges: 34-40%, 27%, 15-22%, and lower scoring ones.

Several people commented that it was difficult to choose a top five out of these needs. Others made comments identifying other needs, with many saying about enjoying what you can do, having a positive mindset and living one day at a time. Similarly, needs around acceptance and motivation were identified, and the need to mentally prepare for the future. Also, knowing if changes in health are to do with HSP or something else, and identifying when a change in care/caring is needed. Additionally, information on discounts or grants for modifications around the home or mobility aids, and having an HSP FAQ which could be given to employers.

Diagnosis and Inheritance

This topic included 11 needs:

Diagnosis and Inheritance Needs	1 st Rank	Total Votes	Score	Percent
Explanation of HSP on diagnosis	126	234	924	100%
Signposting about potential future needs	36	207	652	71%
Signposting about HSP information	21	144	433	47%
Reduced clinical diagnosis time	27	121	393	43%
Having genetic tests available for more types of HSP	29	120	360	39%
Understanding what a genetic diagnosis means	17	128	343	37%
Information on the likelihood of others in family having HSP	15	114	325	35%
Information on the likelihood of next generation having HSP	12	113	314	34%
Signposting about HSP communities	7	115	292	32%
Fewer clinical misdiagnoses	14	87	267	29%
Greater certainty on genetic diagnosis results	9	79	210	23%

Getting an explanation of HSP on diagnosis' is the clear top need in this topic, with 40% of respondents identifying it as their top need. The second need is signposting where to find information about potential future needs. The remaining nine needs are grouped closely together, indicating broad spread of opinion.

Several people made comments, with strong themes around misdiagnosis, around medical professionals needing better knowledge about HSP, and around not wanting to repeat information to multiple doctors. Other themes included; basic information about HSP (variation in symptoms, inheritance, etc.), being told some positive aspects rather than entirely negative perspectives, advice on needing strength of character, receiving information so people don't feel so alone, and coverage of genetic tests on insurance policies.

Wellbeing

This topic included 12 needs.

Wellbeing Needs	1 st Rank	Total Votes	Score	Percent
Information on improving mental health/wellbeing	136	229	957	100%
Information on finding/accessing relevant healthcare professionals	45	188	614	64%
Information on obtaining benefits	22	165	512	54%
Information on communicating with healthcare professionals	30	143	473	49%
Understanding your rights	12	138	366	38%
Information on asking for adjustments at work	18	108	354	37%
Information on finding HSP patient communities	12	110	300	31%
Information on maintaining a good sleep routine	12	99	258	27%
Links with other organisations - larger community	5	56	129	13%
Links with other organisations - shared activities	3	48	109	11%
Understanding discrimination	3	45	96	10%
Information on changing job/career	2	36	73	8%

Information on improving mental health and wellbeing is the clear top need in this topic, with 43% of respondents selecting it as their top need. The next three needs score similarly, covering benefits and finding and communicating with healthcare professionals.

Comments made in this topic were around being able to be heard and understood, and about integrating HSP in with other roles that people have in life. Communication was also mentioned in the context of being able to share details of symptoms with others. Several mentioned having a positive mindset, an active mind, and a higher quality of life. A few seek further information about work, including redundancies, and others seek more information on accessibility and understanding benefits.

Treatments

This topic included 19 needs:

Treatment Needs	1 st Rank	Total Votes	Score	Percent
Treatment options for spasticity	146	219	953	100%
Treatment options for pain	32	141	510	54%
Treatment options for bladder issues	26	131	443	46%
Treatment options for fatigue	21	142	445	47%
Better information on existing treatments	24	139	418	44%
Understanding how effective treatments are	5	81	193	20%
Setting up a patient registry for participation in trials	7	73	177	19%
Treatment options for other 'pure' HSP symptoms	7	63	176	18%
Treatment options for 'complex' HSP symptoms	9	58	167	18%
Development of new treatments	8	66	162	17%
CBD oils/cannabis based treatments	2	62	141	15%
Increased patient involvement in clinical trials	4	55	131	14%
Functional electrical stimulation	6	40	124	13%
Clarity on who is/isn't helped by a treatment	1	53	123	13%
Genetic treatments	6	29	80	8%
Understanding potential side-effects of treatments	1	34	70	7%
Understanding consequences of taking multiple treatments	2	26	64	7%
Surgery options	0	29	49	5%
Re-purposing existing medications for HSP	0	15	26	3%

Treatment options for spasticity is the clear top need in this topic, with 46% of respondents identifying it as their top need. The next four needs score similarly, and are treatment options for the other common symptoms: pain, bladder and fatigue, and having better information on existing treatments. The next block of needs scores in the range 13-20%, indicating a broad spread of opinion.

Respondents identified other pure or complex HSP symptoms that they felt treatment needs for. Symptoms identified by more respondents were: Eyesight, memory, balance, cognitive issues and bowel problems. Other symptoms mentioned included: incontinence, breathing, swallowing, sexual function, stiffness, depression, stress, anxiety, neuropathy, and upper body involvement. Some identified needs around stretching, exercise, walking, strength, changes with changing emotion, and counselling. Several said all of these treatment needs were important.

Some comments were made around other treatment options. Physical treatments mentioned included swimming, massage, yoga, exercise and stretching. Other treatments included art and music therapy, meditation and counselling. Suggestions were also made around, herbs, vitamins, cannabis, botox and diet/weight control.

Information about HSP

This topic included 9 needs:

Information about HSP Needs	1 st Rank	Total Votes	Score	Percent
Predicting how HSP will progress in individuals	76	228	838	100%
Understanding the burden of HSP symptoms	68	194	713	85%
Understanding what the affected genes do	71	170	595	71%
Understanding the day-to-day variation in HSP symptoms	16	194	515	61%
Predicting if other HSP symptoms will start over time	13	154	446	53%
Understanding the prevalence of HSP symptoms	26	130	428	51%
Setting up a patient registry for understanding HSP	21	123	326	39%
Understanding which are the more common types of HSP	5	103	234	28%
Understanding regional differences in prevalence of types of HSP	1	32	67	8%

Predicting how HSP will progress in individuals is the top need in this topic, with 'understanding the burden of symptoms' and 'understanding what the affected genes do' forming a top three group of needs, with similar numbers of people scoring these as their top need.

Comments on this topic were generally around specific pieces of information, including about passing HSP on to children and looking at childhood development milestones and understanding potential for genetic treatments. Several wanted to know information sources for all HSP information.

Mention was made about getting healthcare professionals to share information between themselves more, about getting more involvement from pharmaceutical companies, and more media coverage.

Topic Ranking

Respondents were asked to identify which of the five topics they considered to be the most important and which they considered to be second most important. 305 respondents

answered these questions. Overall, 40% of people selected Living with HSP to be the most important category.

To rank the order of all topics, the number of votes for each of the most important topics has been doubled and added to the number of votes from second most important topics to give an overall score:

Needs Topic	1 st Rank	2 nd Rank	Score
Living with HSP	122	79	323
Treatments	97	73	267
Wellbeing	35	70	140
Diagnosis and inheritance	35	47	117
Information about HSP	17	36	70

Living with HSP was the highest scoring topic in each country except Brasil, where Treatments was the highest scoring topic. People in the UK ranked all five topics in the same order as shown.

Needs Summary

The needs data can be used by HSP support groups, medical professionals and others with an interest in supporting those with HSP to identify how well the identified needs are met. Although wellbeing needs are addressed, The WEMWBS wellbeing scores have not been examined in this analysis because the questions were around identifying what the important needs are, rather than exploring how well they have been met.

Looking at overall patterns:

- Pure and complex HSP have similar distributions of scores, indicating that type of HSP does not change people's needs.
- Wellbeing is seen to become more important as either age or HSP progress.
- Meeting needs around Living with HSP has the potential to benefit the greatest number of people, and is particularly seen as important for young people with HSP and those providing support to those with HSP.
- Treatment needs are seen as important in all groups of people with HSP.

4) Coronavirus

Given the worldwide nature of the Coronavirus pandemic, the opportunity was taken to explore how peoples access to healthcare has been affected.

Number of Appointments

Respondents were asked to report if their number of appointments had changed as a result of Coronavirus Covid-19. The question did not seek to identify any particular types of healthcare appointments. 306 respondents answered the question.

Appointments	All	Well-being	UK	Brasil	USA	France	Netherlands	Canada	Australia
More	5%	(42.1)	1%	12%	4%	0%	5%	6%	6%
Similar	36%	45.4	28%	20%	46%	54%	10%	38%	69%
Fewer	59%	41.1	71%	68%	50%	46%	85%	56%	25%

The group with a similar number of appointments had a higher wellbeing than the group with fewer appointments. There were no differences between use of mobility aids and changes in the number of appointments. The countries where the greatest proportion of people had fewer appointments were The Netherlands and the UK. The countries with the greatest proportion of people with similar numbers of appointments were Australia and France.

Opinions of Digital Appointments

Respondents were also asked if they thought digital appointments were better than face-to-face appointments. 299 respondents answered, with 58% saying that face-to-face appointments were better than digital appointments, 17% saying that these were similar and 2% saying that digital are better than face-to-face. The remaining 21% said the question was not relevant for them.

The proportions of answers are broadly similar across use of mobility aids and countries. The small number of people identifying digital to be better than face-to-face were in the UK, Brasil and the USA. Those saying digital and face-to-face are similar are more often in Australia (38%) and the Netherlands (30%). Of those saying face-to-face are better than digital, the highest proportions are in Canada (75%), the Netherlands (70%) and France (69%), and the lowest proportions are in the UK (43%) and Australia (50%).

Respondents identified their key benefit for digital appointments. 199 respondents answered this question, selecting from a multiple choice question:

Benefit	Respondents	Percentage
Reduced effort travelling	52	26%
Less time taken	40	20%
Less reliance on others to help	16	8%
Reduced costs	9	5%
Feels more personal	2	1%
Other	22	11%
There are no benefits	58	29%

The main benefits for digital appointments are around travel, with reduced effort and less time being the key factors, selected by almost half of respondents. The highest proportions identifying the key benefit as reduced effort travelling generally were those with the highest reliance on mobility aids. The highest proportion identifying the key benefit as less time taken were those who do not use mobility aids or those who use them some of the time.

Of the respondents saying other, reasons included that it was easier to see specialists from other locations more easily, that appointments were covid-safe, and people are able to send their questions in advance. Several commented that digital appointments with neurologists or other specialists were better than digital appointments with their doctors. Some prefer digital appointments because they are self-conscious about their changing mobility.

Respondents also identified their key disadvantage for digital appointments. 290 respondents answered this question, selecting from a multiple choice question:

Disadvantage	Respondents	Percentage
Less chance to show symptoms	152	52%
Feels less personal	46	16%
Issues with technology	28	10%
Feels less important	15	5%
Miss the opportunity to travel	2	1%
Other	16	6%
There is no disadvantage	31	11%

Over half of respondents identify that they have less chance to show their symptoms with digital appointments, and the proportion is very similar across the use of mobility aids. This is the key disadvantage identified with digital appointments.

Of those who said other, reasons include appointments feeling very short or feeling rushed, not being taken as seriously as a face-to-face appointment. Some noted the lack of eye-to-eye contact means it feels like less information being conveyed, and others miss out on interacting with others who have HSP at clinics.

Digital Appointments in the Future

Respondents were asked if they would like to use digital healthcare in the future. 308 respondents answered, with approximately equal numbers saying Yes, No and Not sure. Differences in wellbeing scores for these answers were smaller than 3 points, indicating this is not a factor affected by wellbeing.

Comments to this question were generally re-expressing the advantages or disadvantages depending on the opinion. Notable comments include observing that face-to-face appointments are more memorable than digital appointments, and that with digital appointments it is more easy to hide things like personalities and mental health issues. Many people have mixed views about this, and there are many who have not had digital appointments who would be willing to try. Despite the disadvantages discussed, several expressed the view that it is better to have digital appointments rather than no appointments at all.

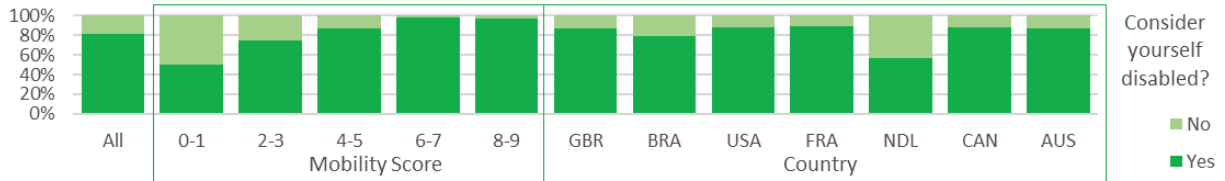
5) Life with HSP

Do you Consider Yourself to be Disabled?

There are 314 respondents who answered this question, as shown in the following grid.

Consider Self Disabled?	Yes	No	Wellbeing Yes	Wellbeing No
All	256 (82%)	58	42.2	45.1
Mobility 0-1	27 (50%)	27	40.9	46.2
Mobility 2-3	43 (74%)	15	40.1	(47.9)
Mobility 4-5	88 (87%)	13	42.8	(42.6)
Mobility 6-7	42 (98%)	1	43.4	-
Mobility 8-9	56 (97%)	2	42.8	-

Four fifths of respondents consider themselves to be disabled and one fifth do not. Although the proportion of people who identify as disabled increases with reduced mobility, there are both people who do not use mobility aids who consider themselves disabled and those who use a wheelchair all or most of the time who do not consider themselves to be disabled. This indicates that mobility is not the only factor in individuals deciding if they are disabled or not.



Those who consider themselves to be disabled have a lower wellbeing score than those who do not. Once mobility aids are taken into account there is a clearer distinction on wellbeing, with those identifying as disabled who do not use mobility aids or who use them some of the time have a lower wellbeing. Once mobility aids are used all or most of the time the wellbeing is similar to the overall average, irrespective of if people consider themselves to be disabled.

How well do you understand HSP?

There are 253 respondents who answered this question, as shown in the following grid.

How well do you understand HSP?	Respondents	Wellbeing
Very Well	58 (23%)	48.4
Well	129 (51%)	43.2
Somewhat	63 (25%)	39.7
Not at all	3 (1%)	-

This shows that half of respondents consider that they understand HSP well. Approximately a quarter consider they know HSP very well, and another quarter consider they know HSP somewhat. Those that know HSP better have a higher wellbeing (5.5 points above average), and those that know HSP somewhat have a lower wellbeing (3.2 points below average).

The proportion that know HSP well is relatively constant across the use of mobility aids, although there is a slight upward trend suggesting that peoples knowledge of HSP increases with the length of time they are affected by HSP. Across the countries, between 52% and 71% of people know HSP well, except in Brasil, where 61% know HSP somewhat. Those in Brasil are the majority (75%) of those who know HSP somewhat.



How well do you feel medical professionals understand what it is like to live with your HSP?

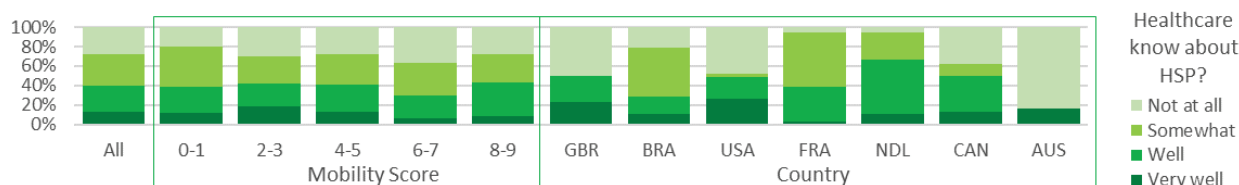
There are 235 respondents who answered this question, as shown in the following grid.

How well do medical professionals understand your HSP?	Respondents	Wellbeing
Very Well	29 (12%)	48.6
Well	65 (28%)	43.0
Somewhat	75 (32%)	43.6
Not at all	66 (28%)	37.1

This shows that one in eight respondents consider that medical professionals understand their HSP very well, and those respondents have the highest wellbeing, 5.7 points above average. Respondents for the other answers are split approximately equally, and those who think that medical professionals do not understand their HSP at all have the lowest wellbeing, 5.8 points below average.

There is a lower proportion (less than 10%) of those that think medical professionals know their HSP very well for those who use frames or wheelchairs all or most of the time. Those who do not use mobility aids generally (41%) feel medical professionals know their HSP somewhat.

Across the countries, most in the Netherlands think medical professionals know their HSP well. In Brasil and France most think medical professionals know their HSP somewhat. In the UK, USA and Australia most think medical professionals do not know their HSP at all.



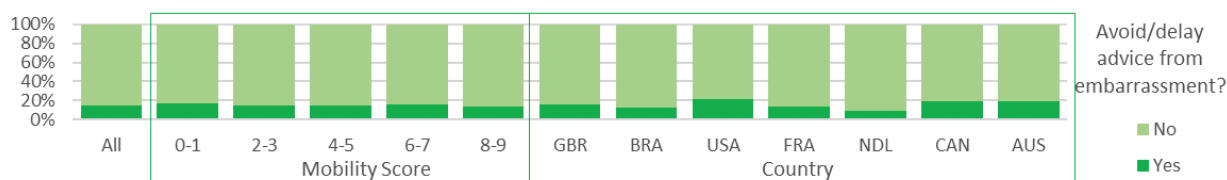
Have you ever delayed or avoided seeking medical advice because you felt embarrassed about your HSP?

There are 313 respondents who answered this question, as shown in the following grid. Wellbeing scores are also calculated.

Delay/avoid seeking advice?	Yes	No	Wellbeing Yes	Wellbeing No
All	48 (15%)	265	35.6	44.2

This shows that about one in seven people with HSP have delayed or avoided seeking medical advice because they have felt embarrassed about their HSP. These people have a lower wellbeing, 7.3 points below average, indicating that being embarrassed about their HSP is an important factor in wellbeing.

There is only a small variation in this proportion across use of mobility aids, indicating that it is not mobility aids themselves that make people embarrassed about their HSP.



What would a cure for HSP look like?

There are 312 respondents who answered this question, as shown in the following grid.

What would a cure for HSP look like?	Respondents
Something which stops the progression of my symptoms	91 (29%)
Something which reverses the symptoms I have	140 (45%)
Something which prevents the next generation from getting HSP	72 (23%)
Other	9 (3%)

This shows that the majority of people would consider that a cure for HSP would reverse the symptoms that they have. There was little variation in wellbeing between these answers. Comments around what a cure would look like generally rephrased one of the three options often with specific details added, or bought two of the options together.

Several went for one-word answers, my favourite of which was that a cure for HSP would be wonderful. One person expressed that a cure when they first started showing symptoms of HSP would have been reversal, but now their HSP is more advanced they would see a cure as just stopping progression. Another, referring to their adult child with complex HSP, observed that a cure to reverse damage would allow them to meet the adult their child they should have been.

Reversal of symptoms had the greatest proportion of respondents across all types of mobility aid, and across all countries, with two exceptions. An equal number of people selected stopping progression and reversal of symptoms in: those who use mobility aids some of the time, and those in the Netherlands.

6) Wellbeing Conclusions

Throughout my survey the different factors which have been shown to have the greatest association with people’s wellbeing have been identified. The tables below draw together the factors which have the strongest associations with people’s wellbeing, either positive or negative. Some of these factors are not shown in this summary, and you should refer to my blog for further details if you are interested.

The number of respondents given is the total number which have or don’t have the factor, irrespective of if they gave a wellbeing score. The needs identified that information on improving mental health and wellbeing was a key need, and many of the needs identified have large over-laps with the issues identified in these tables.

Positive Wellbeing Effect

These factors are associated with people who have a wellbeing which is better than average.

Factor	Respondents	Wellbeing	
See rehabilitation specialist several times a year	17	(50.5)	(+7.6)
Medical professionals understanding your HSP very well	29	48.6	+5.7
Understanding HSP very well	58	48.4	+5.5
Mobility aids some of the time, not consider yourself disabled	15	(47.9)	(+5.0)
See specialist for other symptoms more than monthly	10	(47.8)	(+4.9)
See physiotherapist several times a year	34	47.6	+4.7
Already take part in digital exercise classes	56	47.4	+4.5
Not using mobility aids and not considering yourself disabled	27	46.2	+3.3
See physiotherapist more than monthly	160	46.1	+3.2
Getting adequate treatment after having been taken seriously	139	46.0	+3.1

Negative Wellbeing Effect

These factors are associated with people who have a wellbeing which is lower than average.

Factor	Respondents	Wellbeing	
Delaying or avoiding advice due to embarrassment about HSP	48	35.6	-7.3
Medical professionals not understanding your HSP at all	66	37.1	-5.8
Having SPG7 (diagnosis)	30	37.9	-5.0
Understanding HSP somewhat	63	39.7	-3.2
Seeing a physiotherapist a few times	74	39.8	-3.1

Several of these factors are related to understanding of HSP, either peoples own or that of medical professionals they see. Other factors are around perceptions of HSP, embarrassment or the point at which people consider themselves to be disabled. There are also factors around the frequency which some types of medical professionals are seen.

Those who understand HSP have a significantly higher wellbeing than those who understand it somewhat, and the needs section identifies details of the types of information which people find important. People particularly wish to know about the potential progression of HSP, the burden of symptoms and day-to-day progression.

Understanding of HSP is also reflected in the needs section. Here, needs around having better information on treatments, on finding and communicating with relevant healthcare professionals were strongly identified needs, with several making comments on the need to be heard and understood. Communication issues may be relevant when considering the Ox-PAQ social engagement domain results.

The Importance of Wellbeing

Many of the factors in these tables are not connected with mobility, symptoms or other issues directly related to HSP. The wellbeing factors may therefore not form part of routine

discussions with medical professionals which frequently focus on mobility, pain, continence and the other direct issues or symptoms.

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 embarrassed about their HSP or lack understanding about HSP. Help is available for some factors, and getting such help may improve wellbeing.

These results show that those that already take part in digital exercise classes have a higher wellbeing, and there are many people who would like to take part in such classes, particularly in Brasil, USA and Canada. Needs around stretches, exercises and appropriate physical activities were identified as important.

People may wish to consult with a doctor or other professional to advise on the best approach for any such change they wish to make. Potential areas where changes could be made include:

- Decreasing embarrassment about HSP
- Increasing personal understanding about HSP
- Helping medical professionals understand what HSP is like for you
- Seeing relevant medical professionals at appropriate intervals

Helping healthcare professionals understand HSP and its effects on individuals is an important factor with potential to improve wellbeing in many countries. The effect appears to be more marked in Brasil where people with HSP are often not taken seriously or not believed about their symptom severity.

Adam Lawrence

