HSP NewsLink

LIVING LIFE YOUR WAY

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HSP NEWSLINK

TABLE OF CONTENTS

HSP Newslink

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NEWSLETTER

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Disclaimer: The views and opinions expressed in this newsletter are those of the authors and do not necessarily reflect the views or positions of the HSP Support Group.

Information provided is for general informational purposes and does not constitute medical advice.

CHAIR COLUMN

Hello to all members and readers – those recently starting their HSP journeys and those well-travelled! I hope that you are well, and that our friendly, supportive community continues to be useful. We know that some people can take a while to feel comfortable in our community, especially if their diagnosis is new. We are here to help and support - you are not alone.

AGM

At the end of July, we held our AGM. This was our first face-to-face AGM since Covid. It was a delightful venue in Birmingham, and I have plenty of confidence that we would be able to run a hybrid AGM from this location. It was excellent to see lots of members in person, and the different groups of people chatting in the breaks and over lunch. We were able to record the AGM, and this is now available on our YouTube channel: **https://www.youtube.com/watch?v=Po9WgBxyOPc** Thank you to Penny and June for finding the venue, and to everyone who was there.

Trustees

One important part of the AGM is the election of trustees. All candidates were elected unanimously, and we changed the Secretary and Treasurer. Our trustees for the current year (May 2025- April 2026) are: Adam Lawrence (Chair), Mitesh Patel (Membership Secretary), Helen Payne (Secretary), Michael Payne (Treasurer), Estelle Marshall, Mike Cain, Dave Harris and John Mason. You can find out more details about these people and role changes in the AGM recording. Thank you to John and Dave for their dedication as Treasurer and Secretary.

HSP Book

We are pleased to announce that Pip Lee is writing a book about HSP – "A Beginner's Guide to HSP". There are no books about HSP that we know of, and this will provide useful information for people with HSP. It will be available to buy once complete, hopefully in time for Christmas! Proceeds from the sale will come to the group, and there are more details in the AGM.

Registry

Another new idea is using the new NHS National Disease Registration Service as a registry for HSP. This would allow researchers investigating different aspects of HSP to be in touch with people interested in taking part in such studies, and there is potential for other benefits. We will discuss this at trustee meetings to weigh up the pros and cons. There are more details about this in the AGM.

World HSP Day

The Spanish HSP group has written to the United Nations to proclaim October 17th as the worldwide day for HSP. Spain has been in touch with us and other HSP groups around the world to support their application, which we have done. Unfortunately, the UN do not have sufficient resources to be able to support this. However, there is enough momentum between international HSP groups to self-proclaim. Keep your eyes peeled for things from the SP Foundation in the USA: **https://spfoundation.org/get-involved/events/awareness-week.html**

Euro HSP

On other international topics, Estelle Marshall and I went to Copenhagen at the end of August for a EuroHSP meeting. We heard updates about the EuroHSP research projects and other activities happening around Europe. We took part in several activities organised by the Danish HSP group (**https://sca-hsp.dk/** - hopefully your browser translates to English). We took part in the walk-and-roll on the 23rd, and went to one of their meetings, which you can read about here **https://sca-hsp.dk/2025/08/euro-hsp-temadag-23-august-i-hoeje-taastrup/**

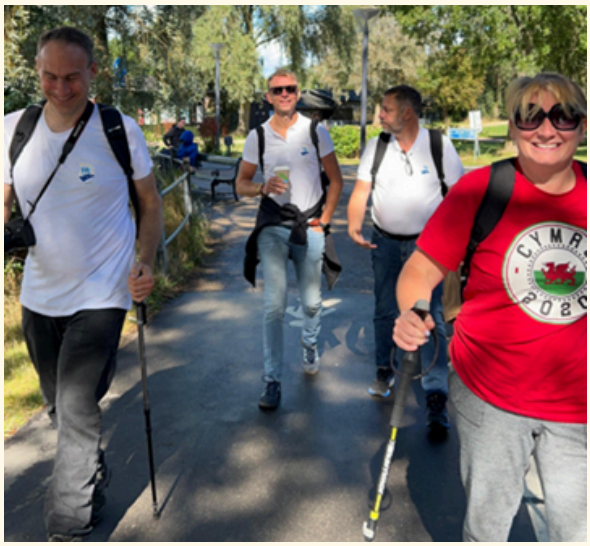
YouTube Update

I conclude by reminding you that we have lots of videos on our YouTube channel. Several topics from recent AGM presentations were relevant to people at the AGM, and you may also find these useful.

There are now links to these on our website:
https://hspgroup.org/links/

The website also has links to all our AGM recordings:
https://hspgroup.org/annual-general-meeting/

Adam Lawrence
Chair



Adam and Estelle at the Euro HSP meeting in Copenhagen

FROM THE EDITOR'S DESK

Welcome to the September HSP NewsLink newsletter!

I have some great news for you!

In the near future, not one but *two* new books on HSP will be published, and both are written by authors with HSP! *The Beginner's Guide to HSP* is written by myself, in collaboration with the UK HSP Support Group. ALL proceeds from the sale of the book will go to the Group to help support members and fund research. The book will cover (almost) everything you need to know about HSP.

The second book, *Living with HSP,* is written by Estelle Marshall, a retired physiotherapist, HSP Group Trustee and regular host for one of the online monthly Zoom sessions. The book will be illustrated with exercise routines for you to follow and tips for living a good life with HSP. All proceeds from the book will go to the Group.

We will send out a special email when the books are available to buy, just in time for Christmas!

In this issue, we feature reports from the EuroHSP Conference 2025, which was attended by our Chair, Adam Lawrence, and Trustee Estelle Marshall. Amanda Snuggs writes about her experience taking part in the Plymouth HSP Study. Finally, two members share their stories – demonstrating the ups and downs of living with HSP.

Throughout the newsletter, I have added links - highlighted in blue – where I think you might like to find out more information. If you click on them, you should be given the option to view the associated website in a separate window/tab. The content should allow you to zoom in and increase the text size.

I would love to hear your thoughts on the content of NewsLink. If you would like to contribute, I'd love to see your ideas. Feel free to contact me at **newslink@hspgroup.org**

Have a lovely autumn, and we'll be back before Christmas.

Best wishes,

Pip Lee

Editor

HSP UK SUPPORT GROUP

Moving Forward Together

The Hereditary Spastic Paraplegia Support Group

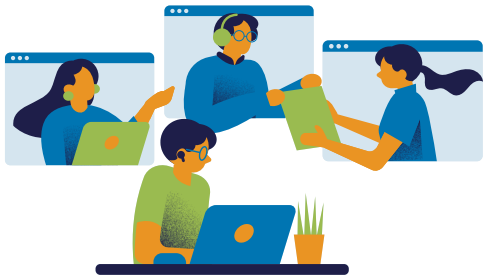
The HSP Support Group is made up of people just like you. We face living with Hereditary Spastic Paraplegia (HSP), whether it is through a personal diagnosis, as a partner, a parent, a sibling or a carer of someone living with the condition. We are a friendly group, and although the condition is varied, it is likely that there's someone you can talk to who has had similar experiences to you.

Whether you are searching for information on a diagnosis, or have a long-term acquaintance with HSP, the HSP Support Group can offer support and practical help in a number of ways – click on the text links to take you through to the dedicated website page where you can learn more:

About the Group – who we are and what we can do for you and your loved ones.
About HSP - what is HSP and how is it diagnosed?
Living with HSP – coping with medical appointments, daily living adaptions and mobility options.
Zoom and Face-to-face meetings – keeping in touch with those of us living with or affected by HSP.
Join the Group – the benefits of being a member.
Donate – your donations fund vital research and projects connected to HSP. We also hold regular fundraising events and appreciate anyone who wishes to take part.
YouTube Videos - an index of videos on the HSP UK Support Group channel

For full info visit HSPgroup.org

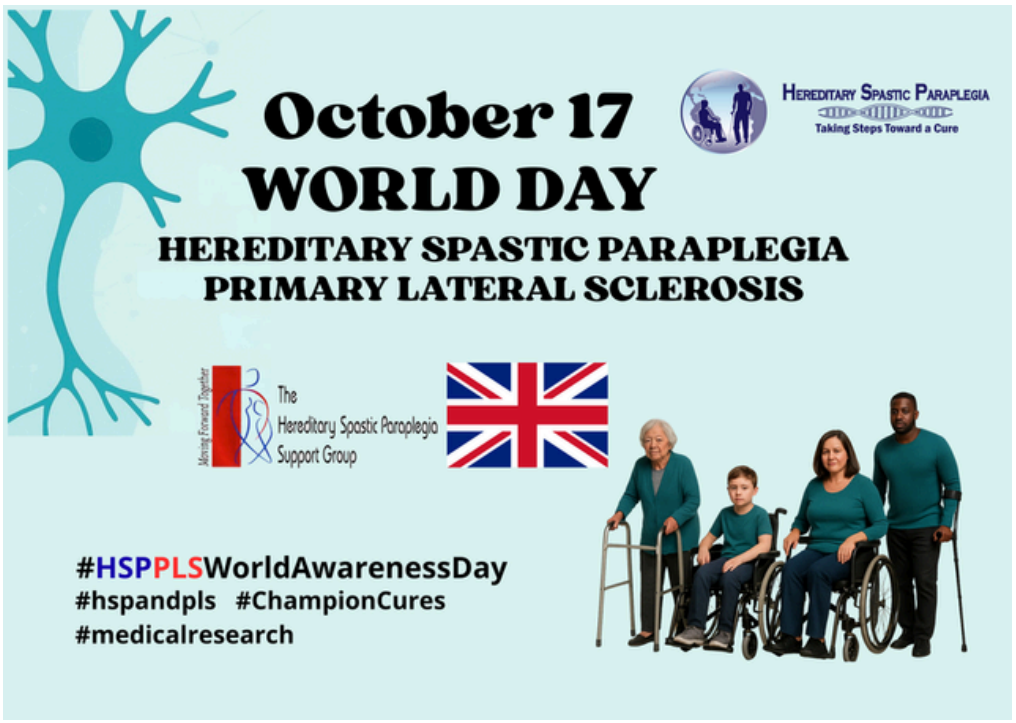
HSP MEETINGS



Meetings are held regionally in-person or via Monthly Zoom, contact details for each group below

Organiser	Meeting	Regional Email	Zoom Email
Jane Bennett	Milford	Milford@hspgroup.org	
Steve and Glenys Browne	Stoke-on-Trent	Northstaffordshire@hspgroup.org	
Mike Cain	North West		Northwestzoom@hspgroup.org
Mike Cain	North East		Northeastzoom@hspgroup.org
Mike Cain	Scotland		Scotlandzoom@hspgroup.org
Penny Cohen	Birmingham	Birmingham@hspgroup.org	
June Masding	Birmingham	Birmingham@hspgroup.org	
Estelle Marshall	Tuesday Monthly Zoom		Tuesdaymonthlyzoom@hspgroup.org
Ian Bennett	Thursday Monthy Zoom		bravoechonovember@btinternet.com
Ian Bennett	**South West (on hold while selecting a new location)**		bravoechonovember@btinternet.com
Hilary Croydon	Feering	Colchester@hspgroup.org	
Kevin Mills	Wales		Waleszoom@hspgroup.org

SAVE THE DATE!



October 17th is HSP & PLS World Awareness Day!

This year, 17 associations and 3 foundations from 15 countries will participate in a coordinated global campaign to raise awareness of HSP and PLS.

Here's how you can take part :

Add Your Photo to the Worldwide HSP Day Frame on Instagram throughout October

Visit the UK HSP Group Instagram page for more details

https://www.instagram.com/ukhspgroup/

Medway Neuro-Tech 25

Meeting report by Mike & Jane Bennett

To celebrate ten years of the Medway Neurological Network, the group organised the Medway Neuro-Tech 25 at the Universities at Medway, Chatham.

Their rationale behind this event was that, 'IT & Technology are playing an ever-increasing role in: Diagnosis, Treatment, Monitoring, Managing & Rehabilitating neurological conditions'. Consequently, the well-planned event enabled both visitors and exhibitors, if desired, to visit stalls from a selection of local and national organisations and charities in the Exhibition Hall, as well as the opportunity to listen to speakers in the Auditorium.

There were the well-known charities, such as MS, Parkinson's, Alzheimer's and Ataxia represented, with the majority of the local ones focused on helping and supporting those with neurological and other disabilities. Most of these local groups encouraged and arranged face-to-face meetings, supporting the development of different skills and limiting the feeling of isolation.

One local group run by Medway Council is FaME, the Falls Management Exercise and Wellbeing Service. FaME is available in a couple of areas around the UK, with the South West focusing on those 65 and over. Medway makes the service available to those living with a range of health difficulties, including neurological disability.

The speaker programme had three themes. First, mobility therapies/wellbeing/creative art, followed by treatment/monitoring/AI/wearables, with the last being communication/speech/screen readers. The speakers were available throughout the day, if further questions needed answering.

A number of the visitors had not heard of HSP, especially young medical professionals who were interested in gaining more information and taking flyers. One lady explained that a hospice resident had been diagnosed with MND nine years ago, only to be recently re-diagnosed with HSP SPG 11. She welcomed being able to take a copy of NewsLink and a flyer with her, as well as contact details of someone with knowledge and experience of this variant.

Using the opportunity to liaise with other charities, we hope to invite those local to Milford to our next **meeting in November.** All in all, it was a worthwhile, productive event.

PLYMOUTH UNIVERSITY HSP RESEARCH PROJECT

Amanda Snuggs reports on her visit to Plymouth University to participate in the HSP Research Project "Modelling Spasticity: A Way of Improving Clinical Teaching"

On 23 May 2025, I attended the Human Movement Lab at Plymouth University to help Gabriela (Gabby) Gonzalez in her PHD research project, which aims to model lower limb movement of sufferers of spasticity conditions, to construct a 'model leg', which could be used for the clinical teaching of these conditions.

Gabby was fully aware of HSP in its various forms and was keen to see my movement (or lack thereof!) I was taken into an examination room with Gabby, another research student, and my husband, Paul. All I could think was that there were no windows in the room and various contraptions and bits of machinery everywhere – what I had let myself in for. There were motion capture cameras and large computer screens on the walls. I felt like I was in Frankenstein's lab, but Paul thought it was fascinating and sat trying to work out the tech behind it all. I thought I was prepared by wearing shorts and having my legs on show, but it was at the point, sat on a medical bed, that I regretted not having painted my toenails!

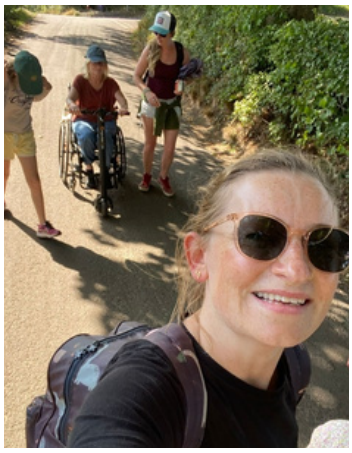
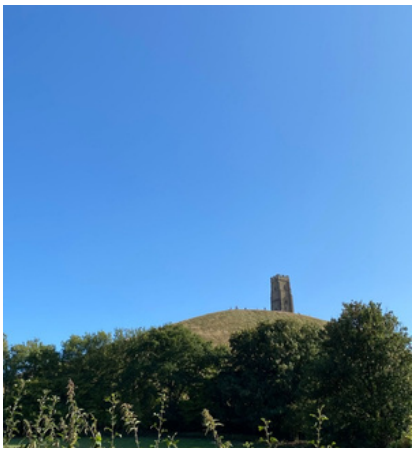
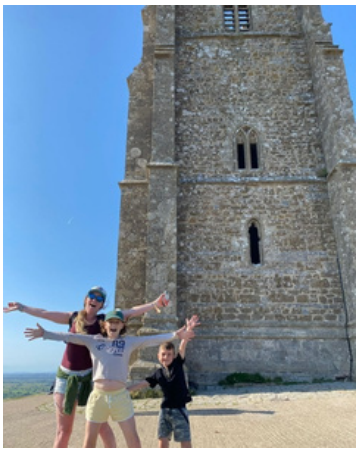
The team of two got started: measured my weight, height, and shoe size, and questioned which was my 'worst' leg. Step forward (or stumble, perhaps being more precise), my right leg, which definitely took centre stage from there. I had lots of sensors taped to my thigh, knee, quads and ankles, which were all linked up to the main computer. It took them a long time and effort to get everything connected to my leg, but once sorted, we were good to go. For the next two hours, my right leg was gently pulled in various positions; I moved it in certain ways, and every little movement was recorded for monitoring on their computer systems.

For one of the 'tests', I had to sit on the edge of a table and let my calf drop down vertically. Gabby lifted my foot to help raise the leg, and then let go. Here's where HSP shows its true colours… if doing this test with a 'normal' leg, you would see the leg fall and swing to a stop – a bit like a pendulum. But my good old HSP leg stayed true to form and flopped to a fixed spot immediately; there was no swinging here! They then looked at the range of movement in the ankle, which was placed into a machine and pushed around by the motor, to measure the reactions of my muscles. It felt like the strangest sensation and was quite a shock! Then it was the turn of my knee; same machine, same tests, again constantly being monitored via sensors relaying the information to the computer.
Next up was walking. I was asked to walk over 10 metres with no aids, no FES, no sticks, and whilst being timed. Then I had to walk again with FES, and they compared timings. I am generally about 40% faster with the FES, which is what we've found at my normal FES consultations.

Once we had finished the physical investigations, I was asked to complete a questionnaire around my levels of spasticity and what it's like living with HSP. Eighty-five questions in total, ranging from 'Can you turn over in bed?' (which was a hard no!), 'Does it affect your relationships with friends and family?' 'Feelings of isolation?' 'How much pain?' 'Spasms?' They didn't miss out on the questions about how HSP affects mental health and any feelings of anger, frustration, and sadness.

Although I went into this research project with some trepidation, I soon felt at ease. Both Gabby and her colleague were extremely supportive and respectful, and continually checked that I was happy with everything being asked of me and that I was happy to continue. Each time we did a new test, they explained fully what was going to happen, why they were looking at this before they started. I felt secure the whole time. The exercises involved do sound daunting – but in reality, they were easy to do and did not cause me any hurt or pain at all. No pain for full educational gain, what more could you want!

As expected, I was absolutely exhausted once we'd finished, but it seemed like a small price to pay for advancing the understanding of HSP. It was definitely worth the journey there and back for a very constructive two hours, and I left feeling like the research team was genuinely doing this to advance the teaching and understanding of this condition. I know research trials aren't for all, but I wouldn't let the thoughts of Frankenstein machines, clinical settings and computer tests put you off. You never know, you might even get a free cup of tea and a biscuit out of it!

A Trek to Glastonbury Tor

by Amanda Snuggs

Recently, I took a day out with my two daughters and three grandchildren to my old home town of Glastonbury. They wanted to reach the top of the Glastonbury Tor - a site suspected to be connected with the legend of King Arthur. Glastonbury is the town that I grew up in, living on a farm with my Mum, Dad, and my sister (who appears to also have HSP 7). I went to school in the town's Abbey convent from age 6 to 8.

We bundled two grandchildren, my wheelchair, my FreeWheel, my Empower F35, my daughter and myself into the car and made the short journey from home (Devon) to Glastonbury. Before long, there was constant chattering, bickering, boredom and general unrest in the back, emanating from the children aged 4 and 6. We finally got to Glastonbury after lots of delays on the M5. Driving through the town, I could see all my familiar haunts: the old convent school, now apartments (what would Mother Superior think?!) I was sad to see so many changes in the town. I might be remembering it with rose-tinted glasses, but there seem to be many 'mystic' shops selling crystals and 'weird' things. This is out of character compared to 60 years ago, when everyone knew everyone by name in the farming community and where we all went to the local church on Sundays. My grandmother and her friends wore hats to church and did not take them off. We were not allowed to talk in the service, and running was definitely out!

We had a long trek up to the base of the Tor from the town, so on goes the Empower F35 to my wheelchair. I call it my pogo stick because it looks so much like one to me – I couldn't even use a pogo stick now, let alone jump up and down! It was 1 ½ miles to the base of the tor, passing by my relatives' houses, which was quite sentimental, with many recollections of growing up there. The ascent to the Tor was quite tricky in the wheelchair, and it got really steep and quite scary in some places. I was glad I had taken my Mirabegron that morning, as my bladder would certainly have had a field day! I had to adjust the power level of my pogo stick from 1 to 2, then 3, which is the highest. I usually keep it on power 1 for flat pavements.

My daughters were helping when cars came by, and gave me an occasional push when I got stuck in a rut, the small front wheel spinning round and not going anywhere! Unfortunately, all three of the old entrances to the Tor from my childhood memory were blocked off by steel gates in an attempt to stop travellers pitching tents near this 'seat of Arthurian vibes'. The Tor has become very spiritualised in my opinion, but it is a well-visited monument attracting all nationalities. We finally found a 'proper' National Trust entrance and some decent paving, and a gate suitable for a wheelchair; I had made it!

I decided not to try the steep ascent to the top, with the tower and the amazing views across Somerset levels, so I got out of my wheelchair and just laid on the grass on the side of the hill, watching the grandchildren scramble to the top and down again. I had fun people watching the visitors making the ascent.

When the grandchildren returned we made our way back down to the town car park, which is a much more sedate descent. We treked through the lanes following my daughter's tech savvy navigation using Google Maps (I haven't got a clue, I just go by 'I know this tree, let's turn left here!') It was so lovely to take time out and have some independence, particularly when everyday life is becoming such a struggle to walk and have a 'normal' existence. All in all, a good day retracing old memories, being with family and having the amazing independence of a wheelchair with a motorised pogo stick on it.

Family Life with a Complex HSP – SPG11

Fortunately, SPG11 is one of the more rare types of HSP because it affects the whole of the body and the brain as well, making it complicated and very distressing to manage.

Although it isn't usually diagnosed until people are in their teens or twenties, it begins from very early on in the form of developmental delay and missed milestones. This is followed by educational problems at school, which may lead to imperceptible progress. At the same time, everything else is difficult too; general coordination and fine motor control issues make practical matters problematic, such as playing sports, tying shoelaces or blowing the nose. It's difficult to find anything a child can do with ease while unaffected siblings breeze through life doing well at everything. This, inevitably, leads to low self-confidence and mood.

While all this is happening, the parents are trying to find causes and solutions but are being 'patted on the head' and reassured as over anxious. Medical and educational professionals fail to listen to concerns. Meanwhile, the parents try to teach the child outside of school hours in an attempt to give them basic literacy and numeracy skills in the hope that they can cope with life in the future, unaware that the child will never be able to.

At some point, perhaps in the early teens, the developmental delay changes to degeneration of the brain and body until, eventually, mobility is impacted and medical professionals start to act, eventually leading to a diagnosis which explains all the varied problems the child has struggled with all their life.

Almost invariably, these children are unable to leave home, and their parents continue as their carers until, eventually, it becomes necessary for the adult child to move into supported living with 24-hour care, so complex are their difficulties. SPG11 destroys several lives every time it hits a family. The care given by the parents involves all personal care and the organisation of every aspect of the child's life: arranging, preparing for and attending a multitude of medical appointments; organising a schedule of activities and providing transport; managing finances and benefits; actively stretching muscles throughout the body and taking the child through strengthening exercises every day; managing double continence issues; sourcing and maintaining a wide range of wheelchair accessible vehicles, wheelchairs and other equipment; and providing psychological support. All this, while watching their child's body and brain close down in front of them.

Most parents say the worst aspect for them is the deterioration of the brain, the dementia. They lose the child they once had, and never know the child as they should be without SPG11. It's too painful to think about the 'might have been'.

– Hilary.

Donating to the UK HSP Group can help fund vital research into all types of HSP, and support members – please consider making a donation today **https://hspgroup.org/fundraising/**