



HSP NewsLink

LIVING LIFE YOUR WAY

ISSUE 59
FEBRUARY 2026

TABLE OF CONTENTS

CHAIR COLUMN

A message from Adam Lawrence, HSP Group Chair

LETTER FROM THE EDITOR

HSP UK SUPPORT GROUP

About the group, membership and useful info.

HSP MEETINGS CONTACTS & INFO

HSP Meetings – info and contact details.

A TRIBUTE TO JOHN MASON

Ian Bennett pens a personal and moving tribute to John Mason.

LIFE WITH HSP - AMANDA SNUGGS' COLUMN

Botox, misbehaving bladders, and electrical stimulation! Regular columnist Amanda Snuggs is back with her witty take on life with HSP.

WHAT ARE TENS AND FES?

A brief explanation (with external links) about TENs machines and Functional Electrical Stimulation (FES) - two ways to manage symptoms of HSP.

HSP MEETINGS & REPORTS

What, when and where! Reports from HSP meetings on Zoom and across the country.

NEUROKINEX – A CHARITY MAKING REHAB ACCESSIBLE

An HSP member's experience of using Neurokinex, a rehab program run by a charity that provides specialised neurological rehabilitation for various forms of neurological disorders.

HSP Newslink



HSP UK SUPPORT GROUP CONTACTS

CHAIRMAN – Adam Lawrence
Email: chair@hspgroup.org

MEMBERSHIP SECRETARY – Mitesh Patel
Email: miteshpatel59@hotmail.com

GROUP SECRETARY – Helen Payne
helenpayne10pwh@gmail.com

TREASURER – Michael Payne

Contact us here: <https://hspgroup.org/contact-us/>

NEWSLETTER

EDITOR
PIP LEE

CONTRIBUTORS

IAN BENNETT
AMANDA SNUGGS
HILARY CROYDON
PENNY COHEN
MARTIN KING

CONTRIBUTIONS

We welcome contributions for articles or personal stories – please email the editor for submission guidelines:

newslink@hspgroup.org

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.

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

I am pleased to report that we have booked our 2026 AGM. This will be on Sunday, 26th July 2026, at the same venue as last year in Birmingham. I'm hoping for a similar level of success as 2025, and it will be great to see many of you there. Further details will emerge as we finalise the day, but you can pop the date in your diary now.

Don't forget that we also run a series of in-person and online meetings throughout the year, so you can use these as a way of keeping in touch with our community.

John Mason

Those of you who receive our e-mails will have spotted our message just before Christmas with the very sad news that John Mason passed away towards the end of 2025. John was an important part of the team running the group, and you can read an obituary from Ian Bennett elsewhere in the newsletter, which sums John up wonderfully.

Rare Disease Day

As many of you know, HSP is a rare disease. There is worldwide recognition of rare diseases on the last day of February, which is Rare Disease Day. You can follow and find out more here: <https://www.rarediseaseday.org/>

On a related matter, I heard a story about someone with HSP who had to spend a long time in hospital. One consequence of their time in hospital was that their mobility became reduced. Here's a quick reminder that if you have a regular routine with stretches or other exercises, you should try to continue that routine when you are away from home. If you are in hospital you may need to advocate for yourself, and seek help from staff to try and maintain your routine as much as possible.

Euro HSP

We have received brief updates from the two EuroHSP research projects. The SPG4 project has identified that whilst the medication being tested, MLN4924, is giving good results, it will need to be reformulated for use with HSP. This medication was originally used for cancer treatment, and would need to be reformulated for potential long-term treatment with HSP. The SPG11/SPG15 project is in earlier stages and is investigating a novel biomarker for these types of HSP.

Paralympics

As I write this column, the winter Olympics are just getting underway in Italy. Once these are complete, we get to watch the more exciting Paralympics! I'm aware of one athlete with HSP, Arthur Bauchet, a French skier, and I think that he will be competing in the Paralympics when they start on 6 th March.

Another HSP Community

My social media has highlighted a new HSP community. I have seen this mostly on Facebook, but you can also see their website here: <https://www.hereditaryspastic.com/> This appears to have started in the USA, and their posts on Facebook appear friendly and useful.

Can you help us?

I'll conclude with a general call for help running the group. We have a few committees which aim to keep on top of certain aspects of HSP. If you're interested in research, fundraising, or generally running the group, and have energy to be proactive in keeping us up to date, drop us a line to say hello.

YouTube

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

FROM THE EDITOR'S DESK

Welcome to the February HSP NewsLink newsletter!

I hope you had a lovely Christmas and New Year – the new shoots of spring are appearing, which brings some cheer!

This newsletter arrives a bit later than I anticipated due to a lot of personal things that have affected my time, focus and energy. Living with HSP (or any chronic condition) adds another layer of stress to everyday life, and even seemingly small things can feel a lot bigger for us. So when something big happens, it can drain us far more emotionally, physically and mentally. We then need to prioritise our own self-care over other activities and demands. Unfortunately, that can leave us feeling we have let people down.

In this edition, we pay tribute to John Mason, former Treasurer of the HSP Group, who sadly passed away late last year. Ian Bennett, veteran HSP Group member and former editor of the Newsletter, has penned a personal and very moving tribute. Our condolences extend to his wife, Sonya, and family, and everyone who knew and loved John.

Our regular dry-witted HSP columnist, Amanda Snuggs, is back with a brilliant article about her diagnosis, misbehaving bladder, and use of electrical stimulation to manage symptoms!

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 spring, we'll be back in the summer.

Best wishes,

Pip Lee
Editor





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 adaptations 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 Monthly Zoom		bravoechoonovember@btinternet.com
Ian Bennett	South West (on hold while selecting a new location)		bravoechoonovember@btinternet.com
Hilary Croydon	Feering	Colchester@hspgroup.org	
Kevin Mills	Wales		Waleszoom@hspgroup.org

HSP MEETINGS – SPRING DATES

AREA	DATE & TIME	CONTACT	ADDRESS
Hitchin & Cambridge	14.03.2026 12.30 - 3pm	hertsandcamb@hspgroup.org https://hspgroup.org/events/social-get-together-hitchin-215-523-718/	Orange Tree Pub 100 Stevenage Rd, Hitchin, SG4 9DR
Milford, Surrey	11.04.2026 3 - 6pm	milford@hspgroup.org https://hspgroup.org/events/milford-april-afternoon-tea-2025-109-831/	The Clockhouse Chapel Lane, Milford, Surrey GU8 5EZ
Birmingham	18.04.2026 12 - 3.30pm	Birmingham@hspgroup.org https://hspgroup.org/events/birmingham-meeting-793-976-562-529-709/	The Kenrick Centre, Mill Farm Road, Harborne, Birmingham B17 0QX
Feering (Colchester) Essex	19.04.2026 2.30 - 5.00pm	Colchester@hspgroup.org https://hspgroup.org/events/colchester-meeting-face-to-face-769-574-255-614-800-112-316/	Feering Community Centre Coggeshall Rd, Feering, nr Colchester, Essex CO5 9QB
Estelle Marshall	Tuesday Monthly Zoom 7pm	Tuesdaymonthlyzoom@hspgroup.org	
Ian Bennett	Thursday Monthly Zoom 7pm	Join Zoom Meeting https://us02web.zoom.us/j/89424187357?pwd=JmNL1Dbg5KW7oKayU2sfrpSEUnUDwr.1 Meeting ID: 894 2418 7357 Passcode: 608387 The above info is valid for every Zoom meeting in 2026	bravoechoNovember@btinternet.com

A Tribute to John Mason - More than a Treasurer

10

by IAN BENNETT



I was devastated to hear of the passing of my great friend John Mason at the end of last year. As many of you will know, John was a former treasurer of the HSP Group, a role that he held for several years. We were so lucky to have found such a thorough treasurer and, with some great assistance from his wife, Sonya, kept our accounts up to date with great precision. What many of you may not realise is that John was far more than a Treasurer. I worked very closely with him during my time on the board, and he was occasionally known to rein us in when we had crazy, overambitious ideas, especially when these involved spending the charity's money. However, he had a gift for knowing what was right and what was wrong and was the first to support ideas and activities that may have initially appeared to be of some risk.

John and I worked very closely together and developed not only a great working relationship but also a very close friendship. John was also a great supporter of regional meetings, and from his experience of being a regular attendee at the Ashburton meetings in Devon, he realised the importance of physically getting people with HSP together. For this reason, John and I had at least a couple of expeditions involving at least one overnight stay, where we tried setting up other meetings around the country. St Helens and Ipswich are two locations that come to mind. These occasions and any other trips we had usually involved a curry and a drink or two, and have resulted in some great memories.

John was very good with IT and compiled a very comprehensive database for the HSP Group, enabling membership records to be kept and enabling communications within the Group. Many of you will know that prior to Pip Lee taking over the role of Newsletter editor, and doing such an amazing job, I compiled 55 editions of the HSP Newsletter. I always liked the Newsletter to be up to a reasonable standard, so prior to publishing it, I circulated it around a team of people, mainly HSP members, who were my proofreaders. I really appreciated any errors these people highlighted, but interestingly, most people usually came back to me with a short list of amendments. John's list was always considerably more comprehensive. He was an expert in the English language and particularly grammar, and I massively appreciated his input here.

For a few years, committee meetings were often held in a pub near Sturminster Newton in Dorset, which is located halfway between where John lived in Trowbridge and where I live in Wimborne. Our secretary, David Harris, like me, a Dorset resident, would also attend these, and once the HSP formalities had been completed, we always enjoyed each other's company. John's wife, Sonya, would always accompany us to these and indeed nearly every other HSP event we attended, and she also became a very good friend of mine over the years, and I'll make sure I keep in touch with her.

My fondest memories of John are the social ones, the drinks and food we had together. I remember John had a gift for selecting the worst item on the menu and then being very jealous of my choice, but he always managed to laugh at this. I remember him staying at my music festival until the early hours before returning to his hotel on his mobility scooter. We seemed to be on a similar wavelength, and I'll never forget the laughs we had together over many years.

My condolences go out to Sonya and family. I learnt such a lot from John. I will always miss him and his great sense of humour. I'll never forget this very special man.

IAN BENNETT

by Amanda Snuggs



“Ok, Amanda, take your shoes off and walk around this table with your eyes closed, please!”

This was my first step towards a final diagnosis of HSP, which came years later! Eight years ago (I’m 66 years old), I went to a highly recommended osteopath with back pain (that’s me with the pain – not the osteopath!) I had never met this lady before, but I just knew lots of people were impressed with her treatment. On my initial visit, she asked me lots of questions and, instead of treating my back pain, just asked me to walk around her couch with my eyes closed. I was puzzled but did what she asked – then came a resounding “I can’t help you. I’m going to write to your doctor with my findings!” And that was it. No explanation at all!

That was the beginning of my journey to a diagnosis of HSP. During this time, my walking was getting worse, and I was getting clumsy, starting to trip up, although not actually falling over. We live in quite a remote setting, and our water supply comes from a reservoir up on the hill. I thought maybe the cows had got into it, and I was convinced there was something in the water affecting me!

It was around this time that I remembered a letter my Father had received in 2012 from my Aunt’s consultant in Bath. The letter was sent to all family members and detailed her final diagnosis of HSP 7. Before this, my Aunt had been wrongly diagnosed as having Multiple Sclerosis, the same as my Mother. We had kept the letter and thought nothing of it, until many months after my initial osteopath visit, when I had a meeting with a very helpful and caring consultant in Exeter. He agreed to send a blood sample to a laboratory in Sweden, but after they could not help, they sent more to Amsterdam for testing. This is when it came back with a final diagnosis of HSP7 (thankfully, all paid for by the NHS).

On the recommendation of the consultant, I started having Botox injections into my soleus and gastrocnemius muscles in both legs every 10 weeks. I have been continuing this treatment for the last seven years, so I’ve now been stabbed around 140 times and counting!

In the beginning, it was amazing. Out of a 10-week cycle, I knew I would get close to ‘normal’ walking between weeks 5 to 8 – during those weeks, I could even walk barefoot and feel every toe touching the floor like elastic! As I wasn’t tripping up as much, I could do more activities, including the never-ending gardening jobs and swimming more lengths than my usual 3! I must admit that nowadays, on the same Botox treatment, unfortunately, it is not as effective as it was in those earlier years, notably due to the progression in my HSP.

One of the other joys that comes with a HSP diagnosis is bladder symptoms. In the last two years, these have definitely become more pronounced for me. But thanks to taking Mirabegron tablets, I can get a good 9-5 pm without running (or more aptly stumbling) to a toilet with quite such urgency and having an accident on the floor. The evening is another matter, however, when the tablets wear off...I'm sure many others are in the same boat.

I have been recently using a TENs pack on short-term loan from the NHS, where electrical pads fit onto my back, each side of the spine, and it gives impulses into the nerves for about 30 minutes every other evening. I usually use this while I'm watching TV (pretty good excuse to sit down if you ask me). I have found that it has a good effect on the urgency and reduces those accidents. As the TENs had to go back to the NHS, I managed to resurrect my old machine from the back of a cupboard (called a Kegel 8), and thankfully, this seems to work in a similar way. I'm sure, like many others, I have been told to do pelvic floor exercises – in all honesty, something I find really tricky. We have so many things we have to do and put in place just to cope with daily life, including the endless leg and foot exercises, to then add pelvic floor exercises to the mix, this is the first thing to drop for me.

The other aid I have been using for the last two years is FES. The physio timed me walking with and without the FES packs, and it turns out I do walk about 30-40% quicker and also stronger when I am wearing them – they've put this down to not having as much foot drop when I wear them. For those who haven't come across them, FES works by attaching two electrodes onto each leg every morning (like small sticky pads), and when switched on, they stimulate the calf muscles when you lift your foot off the floor. There is a sensor under the insole of your shoe, and the battery pack attaches around your leg with an elastic strap. I feel a bit like Frankenstein with all these contraptions – although the grandchildren take great delight in testing my 'electric legs' as they like to call them! I do seem to need these at the moment and see the benefit of them, although if I miss a day, I do go back to my foot cuffs.

All in all, I've found it's definitely a case of keeping active if possible, keeping on going and not giving up! I do my exercises every day and yoga once a week, and try to swim 3 times a week (admittedly only 3-4 lengths at a time but my maths makes that 9-12 lengths a week, which can't be bad!)

I'm still doing a little bit of music teaching on the organ and piano, but have cut down on pupils – currently teaching just three, but I must mention they are all in their 80s, which proves it's never too late to learn or revisit playing an instrument! Having played since I was 15 years old, I've worked out that for me it's easier to play a keyboard, organ or piano than it is to actually walk!

Until next time, enjoy the forthcoming spring and keep going!

Amanda

What are TENs and FES?

Many of you may be familiar with management tools used for symptoms of HSP, but for those who aren't, here's a brief look at the two mentioned in Amanda's article on pages 10-11.

Links to full descriptions of each treatment are in the text - click on the link or copy and paste into your browser.

WHAT IS A TENS MACHINE?

A TRANSCUTANEOUS ELECTRICAL NERVE STIMULATION (TENS) MACHINE IS A PORTABLE, BATTERY-OPERATED DEVICE USED FOR DRUG-FREE PAIN RELIEF. IT USES ELECTRODES PLACED ON THE SKIN TO DELIVER MILD ELECTRICAL CURRENTS, REDUCING PAIN SIGNALS TO THE BRAIN, RELAXING MUSCLES, AND STIMULATING ENDORPHIN PRODUCTION TO TREAT ACUTE AND CHRONIC PAIN.

SOURCE: [HTTPS://WWW.DGFT.NHS.UK/PIL/TENS-MACHINE/](https://www.dgft.nhs.uk/pil/tens-machine/)

WHAT IS FUNCTIONAL ELECTRICAL STIMULATION (FES)?

FES IS A TECHNIQUE USED TO DELIVER ELECTRICAL PULSES TO NERVES TO CAUSE MUSCLE CONTRACTIONS. THE ELECTRICAL PULSES ARE DELIVERED THROUGH SMALL ADHESIVE PADS WHICH ARE PLACED ON THE SKIN.

FES CAN BE USED TO CONTRACT MUSCLES WHICH HAVE BEEN PARALYSED IN CONDITIONS SUCH AS STROKE, MULTIPLE SCLEROSIS, CEREBRAL PALSY OR AFTER INJURY TO THE BRAIN OR SPINE.

FES IS OFTEN USED TO HELP WITH WALKING AND IS USED ON A NERVE IN THE LOWER LEG CALLED THE COMMON PERONEAL NERVE TO MIMIC NORMAL WALKING. IT DOES THIS BY LIFTING THE FOOT AND ACHIEVING CORRECT PLACEMENT ON THE GROUND.

SOURCE: [HTTPS://WWW.UCLH.NHS.UK/PATIENTS-AND-VISITORS/PATIENT-
INFORMATION-PAGES/FUNCTIONAL-ELECTRICAL-STIMULATION-FES-CLINIC](https://www.uclh.nhs.uk/patients-and-visitors/patient-information-pages/functional-electrical-stimulation-fes-clinic)

SPG11 and SPG15 Families Zoom Meeting Report

We have a separate meeting occasionally for these types of HSP because, although they are very similar to each other, they are very different, in some ways, from other types of Hereditary Spastic Paraplegia, most (but not all) of those affected being young adults dependent upon their parents and other close family. These two types of complex Hereditary Spastic Paraplegia are particularly rare, and the few affected families are scattered across the country, so Zoom gatherings work very well for us.

A group of us met on Zoom for a couple of hours for mutual support and to share experiences and tips for tackling various aspects of these HSPs. We were very aware that SPG11 and SPG15 can affect people in varied ways, and also that families will be at different stages of their journey. However, there is much overlap, and all share the emotional and physical stresses associated with caring for loved ones with complex HSPs, especially as we parents get older!

We discussed some spasticity medications and experiences with the baclofen pump. We also explored the support received by families from a variety of different medical professionals, including GPs, neurologists, rehabilitation consultants, neurophysiotherapists, neuropsychologists, orthotists, occupational therapists, speech and language therapists and community teams such as district nurses and neurology nurses. All these can make a valuable contribution to the care of someone with SPG11 or SPG15. One family had been fortunate enough to have benefited from psychological support for the affected person, which often seems to be an area where much-needed help is lacking.

The support available from the Local Authority via a Care Plan was another important aspect and included: support to access the community; personal care in the home; respite and holiday provision; supported living and other alternatives to support when parents are no longer able to care on a daily basis.

<https://www.carersuk.org/help-and-advice/practical-support/>

We discussed applications for NHS Continuing Healthcare provision to cover nursing and care costs; the bar seems very high, and only a handful of families appear to have been successful with this.

<https://www.nhs.uk/social-care-and-support/money-work-and-benefits/nhs-continuing-healthcare/>

It became clear that, when selecting a wheelchair accessible vehicle, it's worth bearing in mind that care workers may not be comfortable driving a large vehicle and, indeed, may not have a driving licence which allows them to drive a car with a manual gearbox at all.

We talked about NHS genetic testing for the extended family, which seems to have become more restricted over recent years, but we hoped that, as costs come down, it may become more widely available, enabling people to plan for the future.

SPG11 and SPG15 Families Zoom Meeting cont...

On the administrative side, we covered CamRare's Rare Patient Passport, which can be useful to show to medical professionals or care staff who are unfamiliar with a particular rare condition. It provides a summary of key information that can be updated and could be helpful to anyone with any type of HSP.

<https://www.camraredisease.org/rare-patient-passport/>

We also agreed on the value of Lasting Powers of Attorney for both Finance and Property, and for Health and Welfare. If a person loses the mental capacity to make their own decisions, these enable someone they trust to speak and act for them.

England and Wales: <https://www.gov.uk/power-of-attorney>

The law is a bit different in Scotland and Northern Ireland.

Scotland: <https://www.mygov.scot/power-of-attorney>

Northern Ireland: <https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

The alternative is for someone to be appointed as a Deputy, which is expensive, time-consuming and cumbersome.

England and Wales: <https://www.gov.uk/become-deputy>

Scotland: <https://www.mygov.scot/guardianship>

Northern Ireland: <https://www.justice-ni.gov.uk/articles/how-apply-become-controller>

There is a Facebook group for those living with or supporting someone with SPG11 or SPG15; if you are in this situation, you are very welcome to join us.

<https://www.facebook.com/groups/1868645340055659>

We're looking forward to meeting on Zoom again. If you would like to meet up, please get in touch with me via the HSP Support Group; I'd love to hear from you.

HILARY

HSP Meetings & Reports

Birmingham October Meeting Report - by Penny Cohen

The Birmingham meeting was held on Saturday, 18th October. It was arranged to be just a chatty get-together, but we had a call from Dr Jacob Day, who is a neurology doctor currently halfway through a PHD at Exeter University, researching HSP with Andrew Crosby and his team. He was interested in talking with the group about their experiences of HSP, their diagnostic journeys and priorities for future research.

Thirty-one people were expected, and we had a turnout of twenty-six on the day. Six new members were expected; four came, as well as two children, who behaved brilliantly throughout Jacob's talk. Everyone was welcomed, and they then enjoyed the usual buffet lunch, prepared by the Kenricks' catering team.

Jacob had prepared a presentation for us, aiming to explain the research they are doing and determine how best things can develop with diagnosis, treatment, prediction and biomarkers. Of the 90 genes associated with HSP, sixteen of these were found by researchers at Exeter. There are still up to 50% of people who don't have a genetic cause found, which means that there are still more HSP genes to find. This is something that they are trying to focus on. The research will be ongoing and hopefully linking up with research in other countries too. Some research in Germany has been looking at the influence of cholesterol on specific genes.

The presentation lasted approximately 20 minutes, leaving lots of time for questions. After this, Jacob stayed with us for further individual questions and discussion. He offered us a link to give feedback after, about how we thought his talk went and what we might individually hope to see with regards to further research.

The next meeting date is Saturday, 18th April, from 12 noon until 3.30 pm.

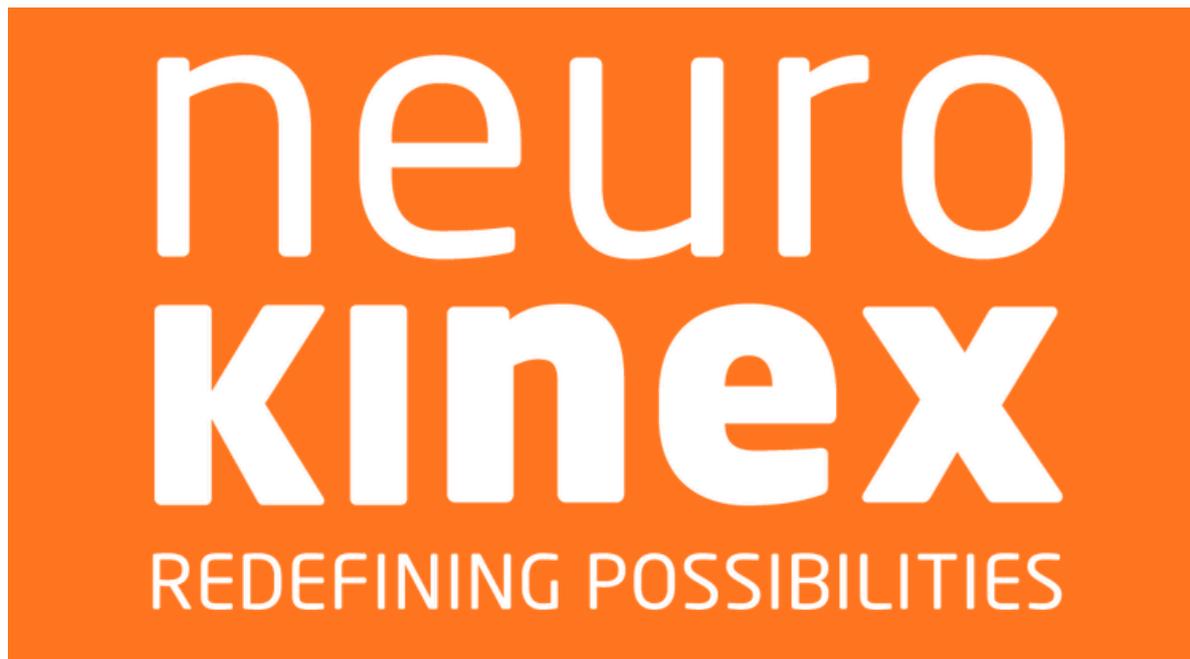
Next Feering (Colchester) Meeting - 19 April 2026

Our next gathering will be on 19th April 2026 from 2.30 pm - 5.00 pm at Feering Community Centre, Coggeshall Road, Feering, near Colchester, Essex, CO5 9QB, and we hope you'll be able to join us.

Feering Community Centre
Coggeshall Road
Feering
Essex
CO5 9QB

Email colchester@hspgroup.org

Neurokinex – a charity making rehab accessible



Catarina Carvalho, Clinical Lead and Spinal and Neuro Physiotherapist at Neurokinex, Hemel Hempstead, discusses HSP member Martin King's progress in using the Neurokinex rehabilitation program.

In 2009, Martin, a middle-aged male, started to notice some changes in his walking and feeling as though his legs “did not work properly”. After a long period of investigation, which is still ongoing, he has been diagnosed with a presumed variation of HSP based on his presentation. As the disease progressed, and he started to have further difficulties walking, he decided to seek professional support to manage his condition. That's how, in 2019, Martin started to attend Neurokinex.

Neurokinex is a network of community-based rehab centres that offer rehabilitation and wellness programmes. Our Activity-based Rehabilitation (ABR) programmes are available to a variety of conditions such as stroke, Parkinson's, brain injury, multiple sclerosis and cerebral palsy. We have centres in Hemel Hempstead, Gatwick, and Bristol, each with a wide range of rehabilitation and exercise equipment.

Martin has been attending Neurokinex twice weekly since then, on top of performing a home-based exercise programme which we review as needed. When he first joined the programme, he presented with increased muscle tone in the lower limbs, reduced balance, gait difficulties, and growing dependence on walking aids.

Goals of Intervention:

- Preserve and improve lower limb strength and flexibility
- Manage tightness and initial symptoms of spasticity and reduce secondary complications
- Maintain independence, in particular, via maintaining walking ability
- Improve balance and coordination
- Enhance quality of life and psychological well-being

Neurokinex cont...

Neurokinex Approach

Across the years, Martin has been provided with a highly individualised programme led by specialist neuro-rehab trainers. He has explored a range of interventions, which include:

- Task-specific gait training focusing on gait quality and activity endurance.
- Spasticity management through regular stretching routines, resistance training, and tone-inhibiting positions
- Balance and core stability exercises, addressing postural control and fall prevention
- Upper limb and trunk conditioning to support independence in daily activities
- Education and lifestyle support to foster autonomy and self-management

Over time, Martin has demonstrated significant improvements in mobility and function:

- Slower rate of functional decline
- Maintained the ability to walk with two sticks over short distances
- Improved balance confidence and reduced fatigue during daily activities
- Increased engagement in social and community settings, contributing to better emotional well-being

Martin is a great example highlighting the critical role of consistent, specialised neurorehabilitation in managing progressive conditions like HSP. Through a tailored and supportive approach, Neurokinex has enabled Martin to maintain mobility, independence, and a high quality of life far beyond initial expectations.

Martin's personal testimonial

As context, I was diagnosed with HSP about 17 years ago when I was in my late forties. My condition has been progressive, from initially only being noticeable when I had too much to drink, to today's situation, when I can only walk very slowly with two sticks. But I am in no pain and have minimal issues with spasticity. I have been going to Neurokinex for about six years, initially once a week, latterly twice a week. Getting there is easy for me as I live close (a 15-minute drive) to the Hemel Hempstead centre and can still drive. My attendance has been very beneficial. On the physical side, results are quite hard to tell as my condition is progressive, but I am convinced attendance has helped me overall and certainly specific issues have been addressed as they have arisen (such as hyper-extension of my left knee and a home exercise programme during Covid). However, I think the

mental benefits are considerable also. Neurokinex is an upbeat place, with all "trainers" and most clients exuding positive vibes. In addition, simply having regular appointments feels good for the soul. In all, Neurokinex has been instrumental in my wife and me handling my HSP.

If I can help with anything, please contact me – mkingdavies@gmail.com

The Neurokinex Charitable Trust (Charity No 1169964) provides specialised neurological rehabilitation for various forms of paralysis. We believe that everyone living with a neurological impairment as a result of paralysis deserves access to high-quality rehabilitation and wellness programmes based on the latest breakthroughs in neuroscience and neuro-restorative research.

Find out more here: <https://neurokinex.org/>