HSP NewsLink

LIVING LIFE YOUR WAY

ISSUE 60
JUNE 2026

HSP NEWSLINK

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The
Hereditary Spastic Paraplegia
Support Group

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The HSP Support Group is a registered charity in England, number 1181539.

CHAIR COLUMN

Hello to all members and readers – those recently starting their HSP journeys and those well-travelled! I hope you are well and that you find our friendly, supportive community useful. We know some take time to feel comfortable here, especially with a new diagnosis. We are here with resources to help and support - you are not alone.

AGM

My first item is a reminder that our AGM is soon. It will be in person, on Sunday 26th July at Sense TouchBase Pears, in Selly Oak, Birmingham. We will run the same format as last year, with the AGM first, followed by a few presentations. We're just finalising details, but we have research teams from London and Newcastle are presenting. More details will be in our letter, which will be sent before the end of June, along with registration, reports and member voting. If anyone can help us stream the event, do get in touch. We're principally looking for someone to operate a camera.

World HSP Day

In another repeat of last year, the international HSP community will be celebrating World HSP Day on Saturday, 17th October. We'll be taking part in that, which is likely to involve an international Zoom call and may coincide with a EuroHSP meeting in Amsterdam that weekend. We'll keep you updated.

Karate Union of Great Britain Fundraising

This year, the 100+ KUGB karate clubs (https://kugb.org/) are raising money for us. This starts at Karate on the Beach in Blyth, Sunderland, on Sunday 28th June. Estelle will be attending to represent the group, and you're welcome to pop along, find out more and say hi. We will put details about this on our website.

New Counselling Service

We're pleased to soon offer members a new counselling service, with a limited number of free sessions. This will be run by RareMinds, a charity providing affordable, timely access to specialised counselling for the rare disease community. More details about them are here: https://www.rareminds.org/wellbeing-hub/. Once we are set up, we'll tell you how to access this.

HSP Open Day in London

Another exciting opportunity this year. When talking with researchers in London, they have offered the chance for an HSP open day at UCL (in London), with opportunities to learn and to chat with consultants and researchers. This is likely to be in the week of 14th to 18th September, and we'll give you more details as they become available.

Childhood Onset HSP Resource

You may recall a few months ago there was a call for people whose children are affected by HSP to participate in a survey. This project is ongoing, and there is now a great website with results and many more resources: https://childhoodonsethsp.org/. It is great to see this resource focussed on supporting younger people with HSP.

CHAIR COLUMN

Do you like to chat?
If you (or someone you know) loves to sit and chat about all sorts of things, then you might consider helping us run meetings in more parts of the UK. Our face-to-face meetings are an important part of our community, but most of our current regular meetings are in the south of England. We have members all over the UK, and it would be great for people to have the opportunity to meet and chat with others on their HSP journeys. We have a fantastic meeting organiser's booklet with the top tips for doing this. Please drop us a line to say hello.

Sailability
Those of you with long memories might remember David Heard talking to us at the 2014 AGM about Sportability. I was chatting with my sister the other day, who likes to go mucking about in boats. She mentioned that the RYA offers a sailability programme that gives people with disabilities the opportunity to sail. **https://www.rya.org.uk/about-us/our-programmes/sailability/** There are different options available, depending on where you are. So, if this sparks an idea, follow the link and let us know how you get on!

Reviewing Your Situation
We know that some of you have regular appointments with neurologists (or others with knowledge of HSP), but some people do not. If you regularly take medication and have not had this reviewed in a while, it might be worth booking up a review appointment. I recently changed my bladder medication with my urologist noting a newer class of medication lowers risk factors for dementia. I'm also now using an intermittent self-catheter, which reduces risks for future kidney problems. You may want a similar review to check that your medications, treatment options, mobility aids and exercise routines (etc.) are right for you. If you find HSP conversations with healthcare professionals difficult, you could look at the HSP patient journey, which gives a great framework for these: **https://www.ern-rnd.eu/patient-journey-hereditary-spastic-paraplegias-hsps/**

HSP Books
A new book, *Living Well with HSP*, was published by Estelle Marshall just after the previous Newslink. This has a great overview of the main elements of HSP and gives space to write answers to the questions that it asks. Having read the book, I can say it has lots to offer. It helps you think about yourself and gives positive steps towards accepting and managing your HSP. You can buy the book on Amazon. As I write this, Pip is just finishing her book, *A Guide to Hereditary Spastic Paraplegia*, which is another resource you can use. More on that another time!

As you can see, there are lots of interesting things in the world of HSP at the moment. I'd like to conclude my column with a big thank you to everyone who contributes. This includes our trustees, our meeting organisers across the UK, people who raise money or awareness about HSP, researchers and healthcare professionals who help us, and people who go about their lives, demonstrating that you don't have to be afraid of HSP.

Adam Lawrence
Chair

FROM THE EDITOR’S DESK

Welcome to the JUNE HSP NewsLink newsletter!

Phew! There’s a bit of a heatwave going on as I write this. I know a lot of people with HSP who suffer from extreme temperatures, so I hope you are managing to keep cool.

Save the Date!

The 2026 AGM will be a face-to-face event held at Sense Midlands, Birmingham, B29 6NA. I will be launching my book ***A Guide to Hereditary Spastic Paraplegia***, which I hope will be a useful resource for all those living with HSP, whether you are newly diagnosed, a veteran HSPer, a family member, or a caregiver. Talking of living with HSP – which is what we do here – Estelle has published her self-help journal, aptly titled **Living Well With HSP**. You can buy the book on Amazon here: **https://bit.ly/4etW7zO**. Looking forward to seeing you at the AGM, if you can make it!

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 enlarge the text.

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 summer; we’ll be back in the autumn.
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.

We are members of **Genetic Alliance UK** and **EuroHSP** (the Federation of European HSP Associations.

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 - 3rd Tuesday of month	Tuesdaymonthlyzoom@hspgroup.org	https://us02web.zoom.us/j/89553715955?pwd=rP1Vz6Jh21Kmn5alZsbRcV2HAGagbu.1
Ian Bennett	Thursday Monthy Zoom	bravoechonovember@btinternet.com	https://hspgroup.org/events/monthly-zoom-meeting-for-all-members/
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
Northern Ireland	Zoom	**Email for details**	**Hspni01@gmail.com**
Northern Ireland	Antrim, NI	**Hspni01@gmail.com**	**Ferrard Room, Clotworthy House Antrim Castle Gardens**

HSP MEETINGS – DATES

AREA	DATE & TIME	CONTACT	ADDRESS
Hitchin & Cambridge	TBC 12.30 - 3pm	hertsandcambs@hspgroup.org https://hspgroup.org/events/social-get-together-hitchin-215-523-718/	Orange Tree Pub 100 Stevenage Rd, Hitchin, SG4 9DR
Milford, Surrey	18.10.2026 3pm - 6pm	milford@hspgroup.org https://hspgroup.org/events/milford-april-afternoon-tea-2025-109-831/	The Clockhouse Chapel Lane, Milford, Surrey GU8 5EZ
Birmingham	17.10.2026 12pm - 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	18.10.2026 2.30 - 5pm	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 Monthy 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

Milford Afternoon Tea- 11 April 2026

Such an afternoon! The day started dull, with the afternoon bringing sunshine and brightness, which very much reflected the Milford meeting. Sadly, circumstances such as ill-health, no dog sitter and enjoying holidays prevented people from joining us.
With the Carers deciding not to have time together, the first part of the afternoon was given to chat and socialising, especially as we had a new member and someone who had not been able to join us since her husband died. As happens, some do rely on family and friends to bring them to the meetings, or car-share with them. To those, we send a big thank you.

We were fortunate to have a 'double bill'. Our speaker was Adam Poulter, a Neuro-Physio from Foundations Physio (**https://foundationsphysio.co.uk/**). He offered to come early to meet the group and watch the demonstration of the Razier II, which Gill, Gary and Jay had brought with them. The Raizer II, as the name suggests, can raise someone from the floor to a seated position, provided another able-bodied person is present to help.
Jay offered to be the patient while Gary explained how the machine works. There are times when someone on the floor can only be raised by ambulance crews, which is expensive, time-consuming, and uncomfortable, but with this machine, both time and money can be saved. The machine is expensive to buy, but with physio support, it is available on the NHS.

Adam described his work and opened a discussion about movement and exercises that benefit those with limited mobility. One exercise Adam promoted was going upstairs, if possible, to strengthen the hip muscles, but the eye-opener for some was going downstairs backwards, which is safer, easier, better for the muscles, and less stressful. Adam encouraged people, when possible, to join groups for activities, as we all benefit from social interaction, conversation, and not doing exercises alone. A number agreed that, having had the benefit of seeing a physio for a set period, the incentive and lack of follow-up afterwards dissuade them from continuing their routines.

The afternoon finished with more chat, laughter and afternoon tea. While I was in the process of finding a speaker, Laura Douglas of Neuro Heroes contacted me. Neuro Heroes provide physiotherapy-led online exercise classes for people living with neurological conditions. They already have a number of members with HSP and understand how important it is to get exercise right – with the appropriate level of expertise, guidance and progression. Here is the link for their Online Assessment form: **https://bit.ly/4eba6JF**

We look forward to seeing people again on Sunday, October 18, from 2 pm until 5 pm. We will still be in British Summer Time then, so hopefully you won't have to travel home in the dark.

HSP Meetings & Reports

Colchester Branch Meeting

We met at Feering, near Colchester in Essex, on 19th April 2026 for our Spring meeting. We were delighted to welcome five new people as well as old friends. There were 19 of us from across the region, chatting over tea, coffee and biscuits and listening to our speaker, Alex from Coloplast.

Coloplast is a company which offers continence solutions for both bladder and bowel issues. These are problems we may hesitate to ask for support with, so it was helpful to receive information and to be shown some of the products available from Coloplast. In addition to creating solutions, the company includes Coloplast Charter, which delivers products to people's homes.

Alex advised that our first port of call if we experience difficulties in these areas is our GP, who will prescribe any products we need and can refer us to other services, such as the bladder and bowel nurses or a urologist, as necessary. Without the referral from a healthcare professional,
Coloplast will be unable to provide free product samples unless we are already using similar products.

For urinary issues such as urgency or leakage, there are various options, although unavoidably, these are more limited for women than for men. Pads and continence pants are options for both, but for those wishing to avoid them, there are alternatives. For men, Coloplast provides the Conveen device, which collects urine and transfers it to a bag worn on the leg and can be emptied later.
https://www.coloplast.co.uk/bladder-and-bowel/male-incontinence/

For women or men, an indwelling catheter (or sometimes a suprapubic catheter) may be an option; again, urine is collected in a leg bag until it can be emptied. Coloplast provides the necessary accessories, such as leg bags in various capacities and night bags that hold 2 or 3 litres. The leg bags can be attached to the leg with either straps or a sleeve, and a stand is provided for the night bag. Both long and short tube lengths are available in the leg bags to accommodate individual preferences. Coloplast uses an anti-kink design in the tubes to promote draining into the bags.

If retention of urine in the bladder is an issue for women and men, intermittent self-catheterisation can enable the bladder to be fully emptied. This can reduce the risk of urinary tract infections, which can be caused by retention

Some people with HSP can experience problems with the bowels, such as constipation or leakage. Coloplast offers bowel irrigation devices that introduce water into the bowel to stimulate a bowel movement, and they will soon offer anal plugs to prevent leakage. Coloplast can also offer stoma care products.

Coloplast Charter is the part of the company which can supply products directly to people at home. When new supplies are needed, they can be ordered from Coloplast Charter, and the company will request a prescription for the items from the patient's GP. Once this is received, the goods will be
despatched by courier and the patient kept informed of the progress of the order. Delivery is usually within 5 – 7 days of the order being placed. Complimentary disposal bags, dry wipes and wet wipes are delivered with the order. For more information on Coloplast and their products **https://www.coloplast.co.uk/**

Other supply and delivery companies are available in this field, and nurses in the community can advise on them.

We shall be meeting at Feering, near Colchester in Essex, in the Autumn and will publicise the date on the website as usual.

HSP Meetings & Reports

Birmingham Meeting Report – April 2026

On Saturday (18th April), a group of around 30 got together at the Kenrick Centre in Birmingham to chat, share and build relationships over lunch. There were new faces and old, and everyone came together around our shared experiences with HSP.
A notable highlight was the Revitive Pro Health that a member brought to demonstrate to others. The Pro Health is a Circulation Booster that relieves leg/foot aches and discomfort using neuromuscular electrical stimulation through the base of the foot. One of our other members informed me that there is another Revitive product (the Revitive Medic) that includes TENS pads for targeted body pain relief, not just through the foot. You can find out more at the Revitive website: **https://www.revitive.com/**

With this successful meeting, we're now looking forward to the AGM on the 26th July and our October Birmingham meeting, planned for Saturday 17th October 2026, where we hope to arrange for someone to come and lead us in some gentle chair exercises.

Service of Thanksgiving for Volunteers – Rochester Cathedral

With many thanks to Phil Bungay from Medway Neurological Network, **https://www.medwayneuro.org.uk/**, we were invited to join The Lord-Lieutenant of Kent and The High Sheriff of Kent Service of Thanksgiving for Volunteers on 12 th March 2026.

This was the second year for this celebration of thanksgiving for all the vital work volunteers do across communities. The cathedral was full with volunteer representatives from a wide selection of groups and organisations, both known nationally, such as RNLI, English Heritage and the Blood Service, plus those local to the towns and communities of Kent, such as Baton of Hope and Street and Rail Pastors. There is the realisation that so many organisations and charities, such as our Hereditary Spastic Paraplegia Support Group, function purely with the help of people enthusiastically giving their free time.

The Order of Service combined is reflective of our location inside a cathedral, including songs from a local community group, but at the end of the service, a light-hearted element were the dignitaries processed down the aisle, to the theme tunes of Hawaii Five-O and The Sweeney.

This was a significant way to acknowledge all the groups that rely on volunteers and all they consequently achieve.

Report from the Association of British Neurologists (ABN) Conference May 2026

by ESTELLE MARSHALL

I attended the Association of British Neurologists (ABN) on 6/7 /8 May 2026.

We had a stand for the Support Group containing a banner, an information sheet on HSP, research questions, copies of Newslink and the book “Living Well With HSP”.

Over the three days, I had many discussions. Two neurologists reported that they had recently diagnosed a patient with HSP and wanted to know about what support was provided by the Support Group. I let them know that we have multiple face-to-face meetings and two monthly Zoom meetings. Two neurologists were interested in the research questions compiled after the 2025 AGM. They reported feeling that the patient's voice was very important. There were a few interested in looking at the book “Living Well With HSP”.

POSSIBILITIES FOR COUNSELLING

I spoke at length with the CEO of Inflammatory Neuropathies, and they do a lot as a support group, including paying for up to 6 counselling sessions through a charity called Rare Minds. He reported that it costs their support group £85 an hour, but that the counsellors are trained in the condition they are dealing with and are specialists in helping people with rare conditions. The emotional impact of receiving a diagnosis such as HSP causes trauma, and this has a large impact on people’s lives.

In addition to talking to people, I attended several of the talks. Some were more useful than others.

MOTOR NEURON DISEASE (MND)

This talk highlighted the importance of Acceptance and Commitment Therapy (ACT) and how the use of this showed a reduction in depression and improved quality of life. One drug that has been successful in treating MND is Tofersen, but it only works for a rare form of MND caused by mutations in the SOD1 gene.

WORKSHOPS

The workshop involved discussion on different topics. There were four tables, and we moved around. The topics were supporting pathway redesign, service improvement and video evidence.

WOMEN AND NEUROLOGY

Much of this was around pregnancy and epilepsy. The importance of pre-conception planning was highlighted, but it was recognised that generally 45% of pregnancies are unplanned. Many of the medications used to treat epilepsy are not suitable for use during pregnancy. The changes in the rate of metabolism during pregnancy mean that the dose needs to be carefully monitored and changed. There is an increased risk of SUDEP (death) during pregnancy, and reviews have shown that some could have been avoided with better care. They also looked at MS and migraines with pregnancy.

Report from the Association of British Neurologists (ABN) Conference May 2026...continued

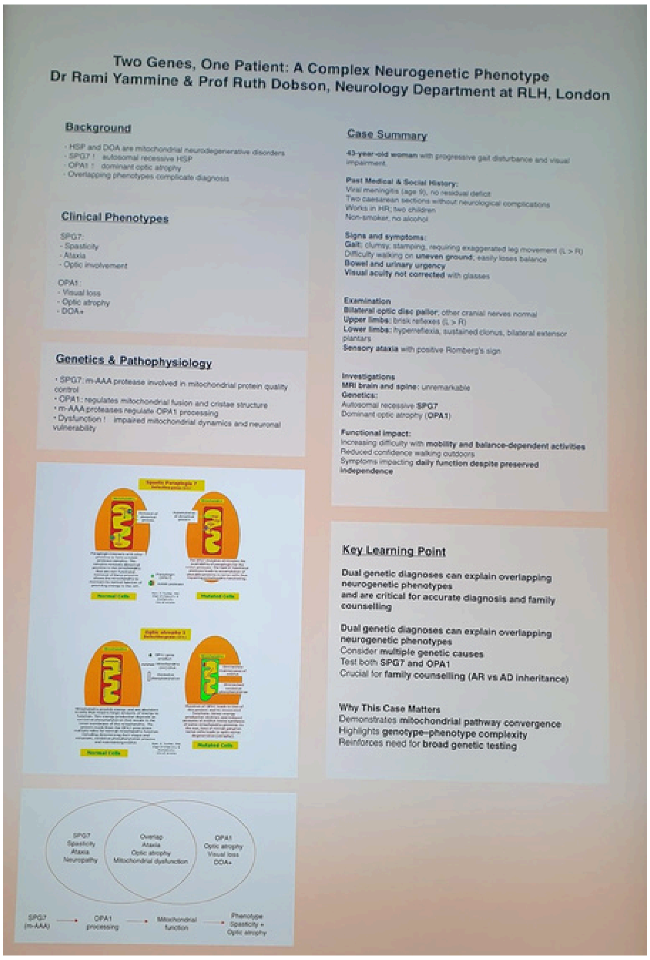
TRANSITION

The problems faced by many patients and families when transferring from paediatrics to adult services were highlighted. A document titled "From the Pond to the Sea" was quoted. Good transitions have been shown to improve health outcomes, while bad transitions reduce them. Joint transition clinics were advised, during which patients could meet with adult services before the transfer. It was advised that preparation is done with the young person and family prior to the official transfer and that support is provided between the ages of 18 and 25.

PRACTICAL NEUROLOGY

The "Practical Neurology Journal" has been published for 25 years. It aims to be easy for neurologists to read; they used a picture of someone in a bath, reading it to illustrate this point.

I attended a few other talks, but there was nothing else relevant from this. I also attended the early morning yoga on Thursday and Friday, because why not?!



Two Genes, One Patient: A Complex Neurogenetic Phenotype
Dr Rami Yammine & Prof Ruth Dobson, Neurology Department at RLH, London

Background

- HSP and DOA are mitochondrial neurodegenerative disorders
- SPG7 ! autosomal recessive HSP
- OPA1 ! dominant optic atrophy
- Overlapping phenotypes complicate diagnosis

Clinical Phenotypes

SPG7:
- Spasticity
- Ataxia
- Optic involvement

OPA1:
- Visual loss
- Optic atrophy
- DOA+

Genetics & Pathophysiology

- SPG7: m-AAA protease involved in mitochondrial protein quality control
- OPA1: regulates mitochondrial fusion and cristae structure
- m-AAA proteases regulate OPA1 processing
- Dysfunction ! impaired mitochondrial dynamics and neuronal vulnerability

SPG7
Spasticity
Ataxia
Neuropathy

Overlap
Ataxia
Optic atrophy
Mitochondrial dysfunction

OPA1
Optic atrophy
Visual loss
DOA+

SPG7 (m-AAA) → OPA1 processing → Mitochondrial function → Phenotype Spasticity + Optic atrophy

Case Summary

43-year-old woman with progressive gait disturbance and visual impairment

Past Medical & Social History:
Viral meningitis (age 9), no residual deficit
Two caesarean sections without neurological complications
Works in HR; two children
Non-smoker, no alcohol

Signs and symptoms:
Gait: clumsy, stamping, requiring exaggerated leg movement (L > R)
Difficulty walking on **uneven ground**; easily loses balance
Bowel and urinary urgency
Visual acuity not corrected with glasses

Examination
Bilateral optic disc pallor; other cranial nerves normal
Upper limbs: brisk reflexes (L > R)
Lower limbs: hyperreflexia, sustained clonus, bilateral extensor plantars
Sensory ataxia with positive Romberg's sign

Investigations
MRI brain and spine: unremarkable
Genetics:
Autosomal recessive **SPG7**
Dominant optic atrophy (**OPA1**)

Functional impact:
Increasing difficulty with **mobility and balance-dependent activities**
Reduced confidence walking outdoors
Symptoms impacting **daily function despite preserved independence**

Key Learning Point

Dual genetic diagnoses can explain overlapping neurogenetic phenotypes and are critical for accurate diagnosis and family counselling

Dual genetic diagnoses can explain overlapping neurogenetic phenotypes
Consider **multiple genetic causes**
Test both **SPG7 and OPA1**
Crucial for **family counselling (AR vs AD inheritance)**

Why This Case Matters
Demonstrates **mitochondrial pathway convergence**
Highlights **genotype–phenotype complexity**
Reinforces need for **broad genetic testing**

THE GREAT JELLY SPOON ADVENTURE

by Lorraine Ney

Sometimes you are confronted with an unexpected question.

I recall an incident when I was leaving my workplace one day, and a colleague stood in front of me and asked, “Why are you limping?” I must say I wasn’t aware I was, so this took me somewhat by surprise. It was a time when I knew something was wrong but didn’t know what, and it was many years before I had a diagnosis, which you will all be aware of, is a bit like trying to build up enough YouGov survey points to receive a reward – it takes years, and you start to think it may never happen!

It was also a time when I had too many other things going on to be ill, like earning a living and looking after my children, so to be confronted in this way was not welcome and a conversation I automatically wanted to shut down. So I looked my colleague squarely in the face and replied defiantly, “I’m not!” That swiftly shut the conversation down, and he skulked away looking puzzled. Of course, he was right. I was limping. When I think back, there had been other comments like this, like “I saw you coming; you have a very distinctive gait!”

Of course, as HSP is a progressive disease, things didn’t get better for me, and as working was just becoming too difficult, I decided to retire early. It was a decision I have never regretted, and choosing not to attempt to go through the rigmarole of trying to retire on ill health grounds, as I was only too aware of the hoops I would have to jump through (poor choice of words, I know!) to go down this route and probably fail anyway, so I saved myself the indignity and stress and cut loose. I knew it would be difficult to explain what the problem was without a diagnosis. Even my doctor just gave me painkillers and told me to take up a hobby. I think even with a diagnosis, it seems few people have heard of HSP and invariably come back to you at some point and ask, ‘what’s that thing that you have called again?’ And those who don’t want to ask and Google “HSP” are faced with a number of misleading results like “Highly Sensitive Person” and just think ‘what a drama queen!”

Once diagnosed, my mind started to rewind like a music tape back to my childhood, and I now think I probably had HSP then, as I couldn't run and jump like my friends; my legs just didn't seem to work very well, but I thought I was just rubbish at games. I remember Mr Tray, my PE teacher, shouting at me to pick my feet up as I made a stumbling attempt at the long jump, landing at the start of the sandpit in a heap. No Olympic career on the horizon for me.

I expect you are wondering what the title 'The Great Jelly Spoon Adventure' has to do with anything. It is a memory I have from one Christmas at primary school, and it was the much-looked-forward-to Christmas party. Bizarrely, we had to bring our own jelly spoon, and even more bizarrely, as I had forgotten mine, I was sent home to get it. To me, this was marvellous news. There was deep snow, and it was about a 15-minute walk to my house in good weather. To make it more exciting, my best friend Margaret Murgatroid Millford came with me. I don't know if she had permission, but we set off together anyway. When anyone asked Margaret her name, she always gave it in full, never missing out the Murgatroid, and always gave a little delighted smile after she had announced it. Three things I loved about Margaret Murgatroid Milford were:

1. She was great fun.
2. My mother disapproved of her.
3. She told lies.

And the three most memorable lies were:

1. She told me her mother was Julie Andrews, which I knew was not true, as I could see her mother did not look like Julie Andrews nor sound like her. This I know, as I had heard her sing, and it was no sound of music!
2. She said she owned a horse that she kept in her backyard, which again I knew was not true, as I could see there was no horse in the yard of her two-bedroom terraced house.
3. And finally, but most horrifically, she told me her mother used to pop her eyes out to clean out the mascara that had built up behind them, which gave me nightmares, and still to this day I sometimes wonder how much mascara is behind my eyeballs!

And so we set off together in the snow for the Great Jelly Spoon Adventure. I don't even remember getting my jelly spoon or whether I even got my jelly. All I remember from that time is, "Wow, I wish I could still walk for 15 minutes in the snow!"