



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 52 – August 2021

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

The HSP 1000 Mile Challenge



This summer the members of the HSP Support Group have been taking on the 'HSP 1000 Mile Challenge'.

This virtual challenge to travel 1000 miles, the equivalent of Land's End to John O'Groats, commenced on 10th July and continues until the 18th September.

Inspired by Captain Sir Tom Moore - this inclusive challenge enables active participation regardless of para-ability. The **HSP 1000 Mile Challenge** aims to raise awareness of HSP and raise funds for important research.

Each week some of our amazing HSP members have been submitting the method and distances they have travelled. When these distances are combined together, they are plotted onto the challenge map that you will see on our website.

To participate, you can use any of methods listed. At the time of writing this article, only 20 members had contributed which is only about 5% of our membership. We would love this figure to be more like 50% of our membership. It doesn't matter how small the length of the journey – all miles and even metres count! A trip to the shops in a wheelchair or walking, walking up and downstairs at home, cutting the grass, daytrips out and about, even a few steps using a rollator – they all help. For those of you willing and able to do longer distances on bikes, wheelchairs, paddle boards, swimming etc – we need you too!

All you need to do is let us know, each week, the distance you have travelled, and the method. If you are techy and have a clever smartphone, or use Googlemaps, this can help tell you the distance you have travelled. If not – don't

worry. We can help work out the distance for you, just get in touch. We'd love photos, videos and stories of your journeys and progress, please let us know what you are up to, so we can share back to the group and encourage others to take part.

To tell us your distance, and share your journey and photos – you can email fundraising@hspgroup.org or use this [form](#), or share on social media with the hashtag #HSP1000 and tag us in at [@hspgroup.org](#) on Facebook or [@UKHSPGroup](#) on twitter.

We will update the [challenge map](#) each week, and keep you aware of the group's progress. As I write this article, we have incredibly reached John O'Groats and we're now seeing how far back we can get. Don't let it stop you from contributing a few yards or miles because all your stories, details and photographs help us and by the time you read this we may well be back in England on our way to Lands End..

The group members can use any of the following methods:-

- Wheelchair (manual or electric)
- Mobility scooter
- Walking (aided / unaided)
- Stair climbing (stairs or stair climber)
- Cycling (exercise bike, arm cycling or cycling)
- Rowing (rowing machine/seated row or rowing boat)
- Running (running machine or running)

- Swimming
- Kayak / paddle board
- Skiing / cross trainer
- Horse riding
- Roller skating / skateboarding
- Sailing
- Water-skiing
- Adult trike.

To follow our progress, take a look at our social media sites, where we'll be sharing our member's journeys.

To support the **HSP 1000 Mile Challenge** you can sponsor us at [JustGiving](#). All funds raised will go to research to develop viable, effective treatments for HSP, leading towards a cure.

Aims of the HSP 1000 Mile Challenge

- Raise funds for HSP research to understand the cause of the condition, improve diagnosis, and develop treatments
- Raise awareness of HSP
- Encourage sporting activities for people of all abilities
- Highlight the capacity that people living with a disability have to lead an active life
- Raise awareness of the importance of a fully inclusive society.

If you can contribute some miles or metres to this fantastic fundraising activity, please get involved.

Chairman's Column

I hope that you all are taking the opportunities to meet up with friends and family now that Coronavirus restrictions are lifting. I know that many people have found the lockdowns difficult for various reasons, and I also know that as the majority of the population strive to head back to their pre-pandemic lives it may feel like those of us with mobility and other issues are being left behind. Please remember that you are not alone, and that plenty of our members are happy to chat. That contact with others can really help with reducing isolation and improving wellbeing.

Trustees Needed

Those of you who were at or have seen the AGM will know that we currently have five trustees. Our constitution allows us to have up to 10 trustees so there is room for more. A trustee is someone who helps make sure that the decisions we take are in line with our objectives, and having a good number of opinions helps us verify that we do. We meet about 4 times a year for a couple of hours

or so, by Zoom. By the time of the next AGM we need to appoint two new trustees for the roles of secretary and treasurer. Trustees do not have to have HSP, but it is useful if they have a keen interest in or connection with HSP. If your partner/siblings/children/friends/relatives might have the right mindset for this then drop me a line – I am happy to talk to explore this issue and ensure that we have a succession plan for John and Dave in place or anyone interested in being a trustee without a specific role.

1000 Mile Challenge

I hope that you have all seen our 1000 mile challenge, which we launched just after the AGM. The concept is simple – any of our members contribute any distance they can to our total mileage. We set the target to getting 1000 miles from Lands End to John O’Groats over 10 weeks from July to September, to raise awareness about HSP and to raise £5000 for research. At the five week point we got to John O’Groats and we nearly got to £5000. We’re getting some great stories about you wonderful members, and we’ve decided to see how far we can get back in weeks 6 to 10. You can log any distances, and should look at our website for details: <https://hspgroup.org/hsp-1000-mile-challenge/>. Thank you to Rachel for this fantastic idea!

AGM

I would like to thank everyone who joined us for our second digital AGM this year. I was really pleased to see so many of you. You can watch the AGM on our YouTube channel: <https://www.youtube.com/c/UKHSPHereditarySpasticParaplegia>. I was very pleased to be able to hear from our award winners this year, Jenni Preston, Estelle Marshall and Jade Bennett. We voted on the group name change. Out of the three options the most popular was HSP UK, however there was also a similar number of votes for keeping the name the same, so we did not feel that there was a sufficient margin to trigger the name change this time. I’d like to thank everyone for voting, and it was good to see how the electronic and postal voting worked. By the time you read this we’ll most likely have had the third of our AGM presentations, and this one will join the other two on our YouTube channel. I’d like to thank Henry, Coralie and Ray for giving us their time.

Meetings

We discussed the resumption of face-to-face meetings at a recent trustee meeting, and we feel that it is time to allow face-to-face meetings to take place again. We will keep the situation with Government guidance/restrictions in view as time progresses. There is one obvious rule, if you have any coronavirus symptoms then you should not attend our meetings. We would prefer it if people did three things: Take a lateral flow test before attending a meeting, wear a face mask at meetings and maintain social distance at meetings. It should go without saying that you should only attend meetings if you are comfortable to do so, I know that many of you really enjoy attending our meetings, and you will need to strike a balance between the risks and the benefits of attending.

Instagram

The group now has an Instagram channel: <https://www.instagram.com/ukhspgroup/>. We set this up to share the 1000 mile challenge stories, and it will continue to share our news once the challenge finishes. We’d love to hear from you on the channel. This channel goes hand in hand with our channels on Twitter and Facebook as well, and you can also find us on LinkedIn.

Blog

Those of you who pay attention to our website will note that our blog page has one entry, from David Hood who shared his story with us. We would welcome blog contributions from other members, they can be short or long. Please drop me a line if you are interested!

Paralympics

I write this paragraph on the opening night of the Paralympics. As far as I understand there are seven athletes in the Paralympics with HSP. You can see:

- Ian Marsden in Team GB in canoe,
- Austin Smeenk in Team Canada in athletics,

- Toni Ponce in Team Spain in swimming,
- Evan Austin and Hallie Smith in Team USA in swimming,
- Rebecca Hart in Team USA in dressage,
- Roman Polianskyi in Team Ukraine in rowing.

Enjoy watching!

Adam Lawrence

Editor's Column

It seems a while since I circulated the last newsletter but at least our lives now seem to be returning to some sort of normality. Apologies for the delay in getting this edition completed but life's been a little hectic for me in recent months. I'm blaming my two daughters, one of whom got married in May and the other one got married in July. Both weddings were amazing but as you can imagine I was busy with wedding preparations not to mention writing two speeches.

I mentioned returning to normality. In addition to the two big weddings, I've been loving the opportunity to get to see live music again, which is something I really missed during the lockdown. Many of the musicians I see are performing outside so I feel Covid safe, especially now I'm double jabbed. As many of you know, the local music scene is a big part of my life and being a regular at events helps me recruit musicians to take part in the Potato Pants Festival. It also helps with my radio show because I like to know about and have witnessed the musicians I'm featuring. The other activity I really missed during lockdown was supporting my football team every other Saturday afternoon. I'm a season ticket holder at Bournemouth and it was so good to be in the crowd again, cheering them on.

Any members who attended our AGM at the beginning of July will have noticed that I am no longer a trustee of our Charity. I've been a trustee for over 15 years which is certainly longer than the charity commission would recommend and I also notice that I don't have the energy that I had when I first got involved. For these reasons, I decided to stand down and concentrate on other activities. Compiling and distributing this Newsletter is one activity that I'll continue with, so please

keep in touch and keep the interesting content coming in. I've also enjoyed hosting Zoom meetings during the lockdowns and noticed a few new faces appearing. Some of these people are members who find attending physical meetings to be physically impossible and seeing how they enjoyed meeting others with HSP made me realise that we need to continue this activity. For this reason, I'll be hosting an informal Zoom meeting on the first Wednesday evening of every month, for anyone who wishes to attend and I look forward to seeing some of you at these events.

I still continue to love using my wheelchair because it gives me so much freedom. I've had a bit of luck regarding this because the council are currently constructing a new cycleway and walkway immediately outside of my home. This new access route will be over a mile long and the parts of it which they've already finished have made it so much easier to navigate on a wheelchair compared to the original pavements. For me, the new cycleway is like a racing track, I can now whizz along at twice the speed. It's a bit chaotic at the moment with all the roadworks and traffic lights but I can't wait until it's finished, I'll be using it daily.

I've recently replaced my mobility scooter. I'm a big TGA Breeze S4 fan, it's so comfortable and does up to 30 miles, so after having two of these in the past, I've just upgraded to the latest model. Although it's too big for shopping, I use it for long trips to town or to the pub or even local music festivals and I take my crutches when I need to access somewhere with limited space. It can even handle being off road so I often use it to go along the river bank which is near my home. I regularly see Kingfishers and I've even seen an otter while scootering along the river bank.

I've actually been out on my wheelchair or mobility scooter most days and I've contributed a few miles towards the HSP 1000 mile challenge. What a fantastic event this has turned out to be with many of our members getting involved. It's also proving to be one of our best fundraising events ever and as I write this, I notice we are approaching the £5000 mark. Well done to everyone who's been involved and well done to Adam's sister Rachel for having this amazing fundraising idea.

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

HSP Meetings – Physical and Online

Unfortunately, it's been 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 organise. 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. Although the trustees have now agreed that physical meetings can resume, I think it's unlikely that there will be a full resumption this year because unfortunately there's still plenty of Covid about and although we realise the importance of getting people together, one of our priorities has to be keeping our members as safe as possible. I'll certainly be delaying Ashburton meetings until 2022.

We've recently been working on the 'meetings' section of our website and the aim is to make it clearer to visitors what we actually get up to and how valuable these meetings can be. We could use your help here. If you're a regular at any of our meetings, we could do with a quote, or a couple of lines from you, explaining why you attend and what value you get from the experience. We'd like to publish some of these quotes on our website to hopefully attract further members or guests to our meetings. I'd really appreciate it if you could send your quotes to me.

As most of you will be aware, during the course of the pandemic, thanks to the Zoom platform we have been holding several virtual meetings. We also conducted our last two AGM's on zoom and they both ran very smoothly with good turnouts.

These 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, or lack of transport options, 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. For this reason, I have decided to host a Zoom meeting for anyone who wishes to attend, on the first Wednesday of every month. These will be very informal meetings where members simply introduce themselves to one another and chat about anything they wish. These Zoom meetings will continue, even when we resume our physical meetings.

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 you'd 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.

Whilst we know there are still risks with meetings, we can't wait 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

Fundraising News

Please read this!

Since I publicised [Easyfundraising.org.uk](https://www.easyfundraising.org.uk) at our 2019 AGM, we now have 60 individuals raising funds for us using this facility and we have raised just over £831.00 to date including £33.16 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 60 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 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 60 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.

Ian Bennett

HSP Award Winners

At our recent AGM which took place on July 3rd, two awards were announced. One award goes to the individual who has excelled in fundraising and one award is given to the

individual who has worked hard raising awareness of The HSP Support Group. The fundraising award was given to two individuals this year. Estelle Marshall and Jade Bennett had both gone the extra mile in the eyes of the trustees and it was felt they both deserved the award. The Awareness award was presented to Jenni Preston for her hours of hard work in creating and maintaining our new website.



Jenni Preston with her award for raising awareness

Well done to the award winners. The HSP Membership really appreciates the hard work that you have put in for us.

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 £1000. 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

Hello to all

My name is Andrew Griffith and I have just joined The HSP Support Group.

I have HSP and having used to be a PE teacher and Maths teacher, have now had to take ill health retirement because of the difficulties associated with the condition. My sister, who lives in France, also suffers with the condition and indicated she was going to do a sponsored walk to raise funds for the research in France into the illness. I was so inspired by this that I decided to do my own little bit to help the support group.

So, on Monday 31st May I undertook a 2.5 mile sponsored walk. The support from friends, family and past pupils was excellent and I kept having to raise my target through their generosity. I was joined on the walk by many of my friends and family who were there to offer balance on my unsteady legs, motivation and encouragement and the chance to finish the walk at my local pub and to join me for a much needed tipple afterwards.



It was a warm day and the walk, although a long distance for my capabilities, went

relatively smoothly with frequent stops to give the legs a rest. The walk itself took me about 3 hours.

At present the walk has raised nearly £2200 for the support group and I am both proud to have completed it but ever so grateful for the generosity and support of so many people.

Andrew Griffith

Tom's Viking Run for HSP

On the 11th September I will be running 17 miles from a village called Riccall in N.Yorks, to Stamford Bridge, dressed in full viking battle gear. Why? Well, my father-in-law has HSP and I've witnessed his struggle with it over the years I've known him. I've always admired his determination and quiet strength of character in the way he keeps cracking on the way he does. About two years ago we got the news that my wife, Becca may have the gene which causes the disease. As I'm sure you all know, it was a 50/50 chance as to whether she would have the gene. If she had it, then our little boy Bertie would have the same chances. At that time Becca was also pregnant with our little girl, Henrietta. Worrying times, to put it lightly.

I approached the HSP Support Group to ask for advice. I wanted to know more about the disease, and start to work out how I can support Becca and the family if it turned out they had it. The charity was very helpful, and I remember them saying "we're here for her" at the end of the call- that really stuck with me.

Thankfully we got the news through that Becca and the children were all clear. Sadly, at the same time one of my wife's uncle and some of her cousins were found or are suspected to have the gene.

Where HSP Support assured me that they would be there for us, I'd like to do something for them.

WHAT ON EARTH AM I DOING!? I'll be wearing chainmail, helmet, (blunt) weapons weighing over 15kg for the run. It's a historic route from Riccall to Stamford Bridge in Yorkshire (and yes, I'll be pre-notifying the

Police). During the battle (of Stamford Bridge...) a 3rd of the Viking army was left at Riccall with their ships, and when the Saxons unexpectedly arrived in force, they were called to join the main army, and fast!



WHY DRESSED AS A VIKING?! Why not? I'm a history nerd, and recently joined a re-enactment group called The Volsung Vikings. See our promo on YouTube below. They're a great bunch of nut-jobs and I feel at home with them.

<https://youtube.com/watch?v=XSMnNFAUjAk&feature=share>

FUNDRAISING At the time of writing, we're on just over £1,600. A few regional papers are also going to help, and the Jorvik Viking Centre have shared the JustGiving post on their social media. With more than a month to go, I'm hoping to smash my £2,000 target. Below is the JustGiving page link. It would be incredibly helpful if anyone could share on their social media, or e-mail around. I'm hoping the quirkiness of it will catch some attention and drive fundraising.

<https://www.justgiving.com/fundraising/tomvikingrun>

I wish you all well

Thomas Bell

Inspiring Disabled Travel!

In late July I went on a short trip to the south coast, namely Eastbourne, Hastings and Brighton with a disabled travel company called Limitless Travel. There were some people on the tour with HSP so, as you can imagine, we had a good chat. I had never been with them before, so I was a bit unsure about them, but everyone was great and we all soon felt like one of the family! We had an excellent tour manager and four super carers, so friendly and helpful. Those that were able transferred onto the coach seats while others could stay in their wheelchairs. Everyone was lifted by a hydraulic lift so there was no problem accessing the coach.



I met them at Dartford Railway Station and we were soon off to our hotel in Brighton. We settled in and had dinner before bed. I hadn't come very far so I was still quite energised, but most of the group got on the coach up north!

The next day after breakfast we were off to Eastbourne and some free time before a cream tea at the Victoria Tearooms. Our next day was to Hastings where we viewed the Shipwreck Museum etc. Our highlight was the British Airways i360 in Brighton. Actually, it was a bit scary looking at the view over Brighton and beyond, especially as it was quite windy!

The important element I got from my trip was 'hope'. I felt that as my mobility worsens, I can still get away. Nothing like the outdoor eg bird-watching inspirational adventures I used

to experience, but at least I know I can go somewhere further afield in the future.



A trip like this to so many destinations in the UK, including the Lake District, Scottish Highlands, Devon the Cotswolds and hopefully, post Covid 19 abroad, may suit many members, particularly if they are alone and want company. Limitless Travel plan and take care of everything so one can just sit back and relax!

I shall certainly be going with them again!

Gary Cliffe

Swimming to Trike Riding

Having been brought up with swimming lessons and always enjoyed messing around in rivers, canals and the sea when I was young, it was always one of my happy pastimes, along with cycling.

HSP started for me when I was in my late 30's/early 40's but didn't stop me cycling until I was about 51.

After receiving some physio locally at about this time, I was asked if I would like to attend the 'Disabled' swimming sessions. I jumped at it, knowing that there were people available to support, it was a great social outlet to network with other disabled people and was the most fantastic chance to get some less stressful exercise in a large pool that was heated just a little bit more for our weekly meets. I made some good friendships there and entered into a couple of galas, surprising myself with winning a couple of medals. They couldn't list my stroke as anything other than freestyle as the legs did their own thing, though the arms were doing breaststroke.

When we moved up from Surrey to Warwickshire, I spent quite a bit of time looking around for more disabled swimming sessions. I found one but the timing didn't suit, so put it on hold. After about 5 years and being kept busy with taking our son to tennis, cricket and swimming club sessions, matches and events, I just popped into one of the local leisure centres that had gone through a refurb and found out that a charity called '1 Leap' were running social sessions on Sunday afternoons. They have 2 large disabled changing rooms at the centre, with their own loos and showers. A whole range of disabilities are catered for. Lots of fun and games go on in the shallower end and some of us swim widths in the deep end. Sadly, when Lockdown started it all came to a stop and '1 Leap' were not able to take any risks with their sessions and so continued the suspension. When restrictions eased generally at the leisure centre, I went along and asked if I could attend the public sessions and take my mobility scooter up to the steps into the pool. They agreed and I was ecstatic. My weight had increased through the Lockdown and I just wasn't getting any exercise. I joined 'everyone active' and downloaded the app on my phone so that I can book a session really quickly and easily. I swim 1 to 2 times a week now and am hoping to make a very small contribution towards the 1000 Mile Challenge.



At the Public Swim, I recognised a lady from the 'I Leap' sessions and we got chatting. We had coffee a couple of times and went out for lunch. When I was sharing with her about my wishes to do more physically and explaining that I couldn't get comfortable on a static bike but had always loved to cycle, she mentioned that she had tried using a trike and thought she had some more information. Later that day she forwarded me some really helpful links. One of these was called 'Parkride'. It's run by Midland Mencap and they have individual and tandem trikes that you can use for free in a park in Birmingham. I asked my wonderful friend June (who also has HSP and a lot of you will know) whether she fancied giving it a go. She was definitely happy to try it and we recently did just that. We had a ball and couldn't stop giggling but managed (with a bit of help from the lovely guys) to travel one and a half kilometres. The struggle was climbing up a slope at the end which had been a lovely downhill freewheel at the start. I was very worried about the effects it might have on my back, hips and legs, but we both agreed the next day that although we knew that we had been exercising, there didn't seem to be any bad side effects. We are booked in to hopefully go once a week now. The plan is to practice a bit more and then we aim to get some miles logged for The HSP 1000 Mile Challenge. I feel incredibly lucky to be able to do this, to have such a scheme available with help and support on site and to have such a great friend to share the experience with.



Penny and June enjoying riding a tandem trike

Penny Cohen

Dear all

I'm a 55 year old man. I have a degree in engineering and have worked in professional management for the entirety of my career... and in several countries.

For as long as I can remember I've had balance/coordination problems... just put down to clumsiness. (Even a school report card from 1970 made reference to my 'lack of coordination' and 'Mark has an inability to play sports').

The problems remained fairly stable, and unchanging, until my late 30s. Although in my mid-20s, I was very much into hillwalking and a friend referred to me being 'as agile as a mountain cow' as a comment on my usual stumbling, and my awkward gait.

My professional career required a lot of travelling. I did notice my ability to carry even light baggage resulted in stumbles, and the odd fall. This was in my mid to late thirties.

In my late thirties to early forties my balance became significantly worse... as well as a degrading speaking ability. I managed to hide the speech issues well, as my job involved a lot of running of meetings and speaking/presenting to large groups.

My job performance degraded as my health deteriorated. In 2009, following worsening balance, coordination and speech I finally concluded that I could no longer continue with my professional career.

After a few scans and standard neurological exams (all negative, or simply advising my GP I was suffering with 'stress and anxiety') I began searching for a definitive diagnosis (my GP simply prescribed homeopathic sulphur pills... which, even now, I suspect was not acceptable... so I did not consider him as a 'route' of assistance).

My father then suddenly died of a massive coronary leaving his spouse of 60+ years alone. I moved back to their home to care for her, then she was diagnosed with Dementia/Alzheimer's and my health concerns sort of took a 'back seat'. I had a further scan (negative) and was referred to a neuropsychiatrist. Nothing happened other

than I was prescribed a maximum dosage of antidepressants which had absolutely no effect whatsoever on my gait, balance, coordination or speech (unsurprisingly). I had the feeling that every medical person had decided that my condition was psychological and they were only searching for evidence that would support this!

Then I cared full-time for mum. I totally ignored my own issues.

In July 2015 she sadly passed away. At this point I moved back to Cardiff (where I was raised). Not wishing to recommence my career (I actually would have been physically unable anyway) I started a business in photographic portraiture. The business struggled... or more accurately I struggled with fatigue, balance, coordination, speech and my walking. I was secretly terrified.

In 2018 I realised how bad my condition was becoming and decided running a business was not happening. I was scared and saw no future.

I lost my home in late 2018 and then suddenly and inexplicably collapsed in January 2019. I lost all memory back to Mum's death, and had no recollection of my move to Cardiff. After 2 weeks in hospital (with negative scans, and psychiatric assessments that showed nothing) I was unceremoniously discharged with no memory, no money, no friends and no diagnosis and driven by taxi to a shelter for the homeless! I sofa-surfed, slept on the streets but was eventually helped by the Salvation Army.

I now have a nice flat, and a diagnosis of HSP SPG7 (thanks to the Salvation Army helping me to be seen by the All Wales Genomic Service) after half a century... and my memory has returned.

I now use a stick and my speech is awful. People assume I have some sort of learning difficulty or mental health problem. Ironically, I feel mentally/cognitively sharper than ever... I just can't get my words out.

As my condition is hereditary (autosomal recessive) my mother and father would have had it. My dad was asymptomatic but

presentations I have now, I recognise that Mum had... but they were masked by her other (extensive) morbidities.

How many people have HSP but are undiagnosed due to a lack of HSP awareness, just as I was?

Mark Orchard

Forthcoming Events

A meeting for all members

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

01/09/2021 7pm, online using Zoom

Contact Ian Bennett: 01202 849 391 or

bravoechonovember@btinternet.com for info

A meeting for all members

06/10/2021 7pm, online using Zoom

Contact Ian Bennett: 01202 849 391 or

bravoechonovember@btinternet.com for info

A meeting for all members

03/11/2021 7pm, online using Zoom

Contact Ian Bennett: 01202 849 391 or

bravoechonovember@btinternet.com for info

Milford Zoom Meeting

Sunday November 21st from 3 pm

Contact Jane Bennett for details.

Kuschall Folding Wheelchair

The Group has recently been donated a used grey Kuschall Ultra-Light folding wheelchair and we'd like to offer this to a member who could make good use of it but we'd appreciate a donation to Group funds. It's suitable for someone of average build, the seat is 40cm X 40cm. It has push handles, brand new Schwalbe Marathon Plus tyres and anti-tip bars. It also has a stick/crutch holder. It's in good condition and these chairs are over £1500 when bought new.

If you are interested in this, please contact our secretary, David Harris.

New Members

We welcome the following new members:

Kylea Hayward Gloucester	Mark Orchard Cardiff	Chanice Charles London
Lu Brown London	Helen Bartlett Pembrokeshire	Shaun Callan Cumbernauld
Jennifer McCaffery County Durham	Andrew Griffith Kent	Gill Court Cornwall
Wendy Watkinson Nottingham	Kenneth Lilley London	Lorraine Holmes Wirral
Dick Van Den Boomen Cambridge	Roger Dowling Walsall	Ashley Looker Blackpool

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

Useful Contacts

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