



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group
Registered Charity No. 1109398

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

HSP – Early or late onset?



Brian and son Jack enjoying a pint down the local

My name is Brian Day. I am 47 years old and have, along with eight other family members, been suffering from HSP since the age of three.

We have only been diagnosed with HSP from the mid 1990s after being labelled with all kinds of conditions before.

In that time I have met many of the HSP group members whilst attending both national and regional meetings.

As I am early onset and therefore only know life this way, I have often wondered, if I was going to have HSP, would I prefer to have developed it late on.

I realise this is an emotive question that may split opinion within the group, however, I wanted to try and cover this topic without being biased.

The majority of members I meet at the meetings are late onset. The fight and drive these people show towards finding methods to combat this common enemy we all share I find inspiring.

I suppose I feel many of my personal battles were won and lost before the age where the late onset members begin theirs. The chances of playing at a decent level of sport or choosing from any career were dashed before reaching school leaving age.

Please do not misunderstand me. The fight to compete has not diminished within. The battle to beat HSP is one of my major goals in life.

To understand both arguments, I need to tell you a little bit about me.

I attended main stream school where the rules were the same for all. These included wearing outdoor shoes, sandals and plimsoles. I used to wear my shoes out every term so the expense for my parents was extreme. Teachers and children could be cruel not really understanding my needs. The world is more understanding these days which is a good thing.

At the age of five, due to constantly standing on my toes, it was decided that an operation to lengthen my ankle tendons was the best solution. A week stay in hospital for each leg followed by 6 weeks in plaster. In those days, parents were not permitted to stay after six o'clock in the wards so this was very distressing for me. I was a bit grumpy at the time of the second operation as you could imagine.

Having early onset HSP and choosing to start a family is an adventure. My Mother, who is affected, had passed HSP onto both my sister, Lorraine and my brother, Les.

Lorraine has four children of which three are affected. I was thinking I maybe lucky as it had appeared to be the women in my family who passed on the condition, but unfortunately my son Jack has inherited HSP too. The first two and a half years Jack was walking perfectly until one day I notice his feet

were not completely flat. Furthermore, because I was looking for the development, I realised that others were looking too. (Isn't human nature marvelous?)

As I have been walking for forty odd years in my own peculiar way with knees bent, swaying to and fro, my muscles are not proportional and my bones in my feet deformed. With various other disorders caused by bad posture, I am sometimes asked if it hurts. The truth is I don't really know. Some days I feel fatigued, have jumpy legs or have back ache but I have managed to avoid taking medicines. I look down at my feet and say "They got to hurt more than they do". Have I become immune?

Considering the late onset argument with the sudden change of life style and speed of progression compared to the early onset, which can be fairly static for many years, my vote would go to not having late onset.

I just experience a moment of brief irritation when I hear comments from late onset members who tell me it is worse to have HSP later when mine and my family's dreams were shattered before having a chance to live them.

I wanted to be a fireman - a hero running into burning buildings to save all. I would probably be near retirement now.

My sister Lorraine, probably the most compassionate person I know, wanted to be a nurse.



Lorraine & Brian out celebrating the recent festivities
It wasn't to be. I also speak for Lorraine when I say we are not bitter.

Sympathy, I believe, is a negative force to be repelled at all costs. Humour is the key. I found if you can laugh at yourself and your situations, the bullies and moaners have nowhere to go.

Brian Day – Region 1

Chairman's Column

I hope you've recovered from seasonal festivities and that you're keeping warm and as healthy as possible through the winter months. Spring will soon be here and at least we've been fortunate as it hasn't been a bitterly cold winter. I always look forward to those early spring days when you can first feel a bit of warmth in the sun and they're getting closer.

Thank you to all members who've provided such interesting content for this edition. I can only make the Newsletter as interesting as the content I receive, which is mainly from our members, so please keep the articles coming in.

This is the 25th edition of our newsletter in its current format and you'll notice that two members have written poems for this issue. I don't believe we've had any poetry in the past so maybe this is the start of something new. If you have any interesting news or opinions (or poetry) to share please let me have it in time for the next edition.

Some time ago I set up a Facebook Group to enable members to share information. Although it took a while for this facility to become utilised to any significant level I'm pleased to say that it has recently become fairly busy. It now has 100 members from around the globe, so if you use Facebook and haven't registered, please do so and introduce yourself. On Facebook, search for 'Hereditary Spastic Paraplegia's Unite' and you will find it.

I've heard from a few members recently who are very concerned about planned changes to benefits and what financial effects this may have on us. If you have any knowledge or experience of this, please share it with us. Hopefully we can put a few minds at rest.

Another discussion topic that has been prolific recently is the merits of taking Baclofen and other antispasticity drugs orally. I'm very aware that without exception, those who have an intrathecal Baclofen pump fitted benefit significantly. However, it occurred to me recently that in all the years I've been involved in the group, I've never heard anyone singing

the praises of drugs such as Baclofen and Tizanidine taken orally. I'd appreciate some feedback on this, particularly if anybody does find such drugs life changing in a positive manner.

I've discussed fund raising a lot recently and particularly how much of it has been taking place. Thank you to all members who have been involved in fundraising for us in recent months. Although it's difficult for all charities in the current economical climate, HSP fundraising activities certainly aren't going to stop. To date we've had no success in approaching charitable trusts, but we won't give in. I'm looking forward to the next meeting in Ashburton on March 31st (all welcome) where I'm aware further mad fundraising schemes will be discussed. I've had email communication recently with a member's daughter who is going to run the London marathon this year raising money for us. With funds raised, we'll continue to support research teams and help members to purchase suitable mobility aids.

Going back to Devon meetings, the next one on March 31st will be the 10th anniversary of such events. Please try to join us if you can, particularly any members who've attended these meetings in the past. I clearly remember our first Region 4 get together at The Holiday Inn on the outskirts of Exeter and it would be great to see some of the members who attended that event join us for our 10th anniversary. I know that the Dartmoor Lodge Hotel in Ashburton is now fully booked for Saturday 31st March, but if it's within driving range, please join us on the day from 2pm.

The Committee have begun organising this years AGM which once again will be held in Leamington Spa on June 16th. We already have a couple of speakers organised and I have a good idea for a third. Please try to keep the day clear and join us if you can. Everybody is very welcome. Full details will be included in the next newsletter which I'll endeavour to produce and circulate in early May.

As always, I look forward to meeting up with many of you at events during the year. Keep in touch, keep stretching and keep well.

Ian Bennett

Secretary's Spot

I let myself in for a little job before Christmas by volunteering to set up a system for members to communicate with each other by email. We'd had one working for several years hosted by member Phil Stringer. Phil has now retired from his job and it was necessary to find another place to "host" the emails.

This was simple in concept - the twelve co-owners of the narrowboat that Carolyn and I have a share in had been running such a system for five years on "Google groups" and I had been administering it without problems.

So I volunteered to set up the replacement email system....

What I had not realised was that in the time since I had set up the earlier, small system, things had changed on Google groups: Where it had been possible to simply add email addresses to a list, it was now necessary to send an email invitation to each person. Moreover, each person had to reply to the message before "the system" would allow them to join.

To compound the frustration, it became quite apparent during the set-up phase that many of the invitations and replies were simply not being delivered. It began to look as though I'd opened a can of worms which was getting bigger by the day.

I now decided to search around to see if others were having the same difficulties. I was pleased to find out I was not alone. However - no-one had been able to solve these unreliability issues with Google groups. Further information came to me suggesting an alternate organisation (Yahoo) which might host the system. A bit more research seemed to show that this approach did not suffer from the same problems.

I bit the bullet and started to load all the email addresses into the new system. After just under two weeks I had all the addresses loaded and all our email equipped members were able to converse again.

If you want to join the system, you can do by sending an email to : [hspgroup-
subscribe@yahoogroups.co.uk](mailto:hspgroup-subscribe@yahoogroups.co.uk). It may take a

day or so for one of us to approve the request.

Similarly people may leave the system at any time by sending an email to: [hspgroup-
unsubscribe@yahoogroups.co.uk](mailto:hspgroup-unsubscribe@yahoogroups.co.uk)

I'm pleased to say that since we completed the set up things seem to be working well - it is almost a month old now and we don't seem to have had any problems. Well over 100 of us are able to converse and share our experiences again by email....

Dave Harris

In Loving Memory of Joy Kathleen Utting



28th July 1938 – 12th December 2011

Joy died peacefully at home on 12 December 2011 aged 73 years after a long battle with HSP and then Motor Neurone Disease.

She had been a primary school teacher until 1992 when her troubles started with a brain haemorrhage. Amazingly she survived this, and Joy and Paul spent many happy years of retirement in their campervan visiting the countries of Europe. Joy's balance had been affected, and the campervan proved to be an ideal vehicle.

In 2001 she started having falls, and referral to her surgeon at Southampton did not explain her problems and she was eventually diagnosed the Idiopathic Spastic Paraplegia. It

was around that time that she joined the HSP Group.

What a difference that made to her. She was determined to make the best of her life, and the HSP Annual Conferences in Peterborough in 2004, we heard a presentation by Prof Nick Wood of the Hospital of Neurology and Neurosurgery in London, about the genetics of HSP and more importantly an invitation for a referral to see him there. That led to exhaustive tests which eventually in 2008 led to a diagnosis on MND.

At another HSP meeting at Milford in April 2004 we had a demonstration of the Odstock Stimulator given by a private Physiotherapy clinic called HeadsUp from Dorking. We made enquiries with our local Portsmouth NHS trust who did not then provide funding for the stimulators. So we decided to go ahead with 2 stimulators privately. And what a difference they made also. Joy was able to walk much better and not trip over her toes. Then shortly after being told no funding was available we had a letter from Odstock saying they now had funding and Joy was issued with a two channel stimulator. She benefitted from this until 2009 when her mobility started to suffer.

Eventually Joy lost the ability to walk and stand, so by the end of 2009 she needed more care. Initially it was just help for one hour in the morning and this built up to 24 hour live in care from August 2011.

Joy has received tremendous help and support from the HSP Group. She especially enjoyed going to Region 1 meetings organised so ably by Jane and Michael Bennett. And latterly she had amazing support from the MND Association at both local and national level, from the local Rowans Hospice in Havant.

Towards the end she had an army of NHS professionals looking after her various and many and changing needs. She inspired many people by her courage and her lovely smile, even though she eventually lost the ability to speak and swallow. Her quality of life was very poor, communication became very difficult, but Joy never complained. She will be sadly missed by her family and many friends.

Paul Utting Region 1

Useful Information

HSP Cruising

We booked a cruise in September with Sonya's dad. He discovered cruises several years back and persuaded us to join him for the first time three years ago. I was more mobile then and could cope with everything using a single stick. This time was going to be more difficult; I have far less confidence in travelling and use a scooter to get around outside of the house.

The first hurdle was that one cannot take a scooter on board a Thompson's ship, it has to be a wheelchair. The second hurdle was that there were only 4 wheelchair accessible cabins on the ship so it was best to book early. You are not allowed to use a wheelchair on board if you are in an ordinary cabin.

We left from Bristol airport and flew on a Thompson flight to Dalaman in Turkey. Getting on the plane was easy, we had pre-booked assistance and this required reporting to a desk half an hour before the flight and I was then pushed in my wheelchair to a vehicle that delivered us to the plane. It was a walk of only a few feet to our seats so it was all really very easy. At the Turkish end there was an air bridge and the wheelchair was waiting for me at the plane's exit door. Dalaman is a much more modern and accessible airport than Bristol!

Once on the ship getting around in a wheelchair was easy. There are lifts between decks and the staff are always eager to help. We felt very well looked after. There was even a notice on a table in the theatre "for wheelchair users only" so there was no fight for somewhere to sit. Getting onto the deck through the double storm doors was not easy but there was always someone, crew or fellow passenger, who was eager to help.

I only found one disabled loo on the ship, and that was just a bigger loo, so I had to visit the conventional toilets most of the time. I can walk a few steps with sticks so that was okay but we were fortunate in that the sea was dead calm the whole week, it would have been much more hazardous if I had had to cope

with the movement of the ship. The other loo problem was during the night. While there was plenty of space in the cabin there was quite a steep slope up to the bathroom. Again, I could manage it but it was too steep to get a wheelchair up there with or without help. My conclusion is that the ship caters for a certain level of disability.

You make lots of visits to restaurants on a ship and without fail we were looked after very well indeed. In the self-service restaurant a waiter would grab a tray and push me along the self-service service counter putting whatever I wanted onto my plate and then he would find a table for us. In the formal restaurant where we ate each evening we were whisked to a table, a chair removed so that the wheelchair could be slotted in. We could not fault the staff, they were all so friendly and helpful.

The last thing to consider are all the excursions. Of the five days in various ports we took excursions ashore on three of them. The obstacles are getting onto a coach and then navigating around the sites visited. The tour reps always ensured that seats at the front were reserved for us. Istanbul was fairly easy. Where the regular tourists had to queue and take their shoes off to get into the Blue Mosque, we bypassed the queue but had to transfer to a 'clean' wheelchair to gain access! We visited the Blue Mosque, Hagia Sophia (this is a stunning building 1400 years old) and the old spice market (this was fascinating). Apart from the occasional uneven pavement we coped rather well.

Athens was another excursion with a sightseeing tour and some free time in the old quarter. There were no lowered pavements in the old city but we were able to use the roads as there was little traffic. We had lunch and a loo break. The cafes and restaurants have their loos downstairs so, again, if you can walk a few steps you are okay.

The last excursion was to Agios Nikolaos, a nice little port on the north coast of Crete. The pavements there are all equipped with disabled ramps at the street corners so it was quite easy to get around. Two excursions we could not go on were to Ephesus (as the site is not at all wheelchair friendly) and Lesbos (as

the ship did not dock so transfer to the island was by tender). We didn't mind, as the weather was good and it was still a pleasure to relax with a good book on the promenade deck and to have the ship virtually to one's self.

To conclude, the week was really enjoyable and I thoroughly recommend a cruise in the Med.

John and Sonya Mason Region 4

Trip to Argentina

As the saying goes, the world is getting smaller, but for those of us with limited mobility, the decline in the size of the world has a different connotation. When travelling we need both the reassurance that vital facilities will be available and that we can get around in the means we are able to.

Travelling somewhere not knowing what is available, is an adventure but also risk, even though I know Michael is there to support and help me.

Fortunately for me, my HSP was diagnosed when in my mid twenties, so we had time to fit in more adventurous journeys whilst I was still able to get around. Now the lower limbs are not as strong as they were the destination of choice has to be tempered; no more crawling along the Chu Chi tunnels in Vietnam!!

Argentina was our destination in March. What an experience. We travelled from Buenos Aires up to the Iguazu Falls using air travel once but primarily we used their comprehensive bus network. Nine towns and cities in eighteen days was our itinerary.

The bus network has developed as an economical way of travelling long distances. Most of the buses are double deckers but not as we know them. The lower decks (where the toilet is located) are great if you have limited mobility. Cama Suite is the 'business class' for overnight travel as you are served with a hot airplane type meal, with soft drink and a glass of champagne before you tuck down in your seat that transforms into a bed, with pillow and blanket for the night. If you can't sleep there are in-house movies and free Wi-Fi. Near your destination you are woken

with a breakfast snack tray and hot drink in the morning.

The cities visited were a cross section of Argentina. We went to Mendoza for the wineries and to experience the Andes. Cordoba for the history and architecture. Rosario, where both Che Guevara and General Belgrano (the designer of the Argentinian flag) were born. San Ignacio was a site where the Jesuits set up missions to protect the indigenous peoples from Slavers. Two priests to deal with up to 10,000 natives.

Yes, there were facilities for the disabled, and the wheelchair symbol was visible on certain doors, but having to walk up a couple of steps to get to the door somehow defeated the object. Steps and stairways are everywhere, rarely with the option of lift or ramp access.

The Iguazu Falls should be viewed from both the Argentinean and the Brazilian side. The Argentinean side is more disabled friendly, with a train to take you to the falls and wide walkways, step free, to see the falls. Yes, there are a couple of view points that have steps, but the majority are easily accessible, unlike the Brazilian side, where steps are plentiful.

Jane Bennett Region 1 & 2 CO-ordinator

Members' Letters

Dear Ian,

My own profile. Born 3/ 11/42

I have some recollections of tripping toes and certainly pigeon feet by age 35. At this stage my mother was in difficulty and her Doctor suspected alcohol (obviously not). She attended the Masonic Hospital and this may have been about 1965 but the condition was not recognised.

For my own part, Doctor Robert Danbury at Bromley, who had advised my oldest friend Andrew on rugby injuries, agreed to see me and initiated some stretching exercises especially for the arch at the base of my spine. I told him that I had received some physiotherapy at Crayford where I was given a General Anaesthetic and "pulled" by 2 strong men. Dr Danbury was horrified and referred

me to Mr Kevin Zhilka at Kings College Hospital, Denmark Hill who diagnosed FSP.

When I explained to Mother she was aghast at the suggestion she was Spastic, but at this stage I was (just) able to look at the Web and obtain information from America on the condition which was largely still unknown to General Practice. I played rugby for Rochester and the Old Gravesendians but to my great surprise and dismay, I discovered in a squash match with another club, that I could not run. At this stage I took up Indoor Bowling and then Croquet. The former I can still manage from a wheelchair but the latter is now impossible due to the distances and time scale involved.

I have just decided not to drive my Citroen Tsara Picasso automatic without hand controls, so have had my driving assessment and am about to get the car adapted.

Our recent problem has been Prostate Cancer 20.58 PSA which now after Radiotherapy has reduced to 0.11. My right leg is tending to collapse and I can just get around with 2 sticks. We use a folding wheelchair to "go out".

I have an Attendance Allowance and my partner has just applied for a Carers Allowance.

Best regards,

Michael Jarvis Region 1

Dear all

Some years back, frustrated and in pain because of the NHS's long waiting list for physiotherapy, I went private and was fortunate enough to be treated by a Physiotherapist who told me that my problem was that I had no power in my lower legs. After some more testing, he then realised that my mobility problem was neurological. As I had had a bunions operation on both feet fifty years earlier, and had always related my back, leg and foot problems to this (the operation was Keller's and should not have been performed on a patient in her early twenties), I had always assumed that this was the source of my problems. My GP had never suggested that I go to a Consultant to have the various

symptoms arising over times investigated, and my condition diagnosed. The London Teaching Hospital where my operation had been done provided me with orthotics over the years, but by the time I was in my fifties, I was searching round for other solutions, including Homeopathy. This led me to a homeopathic chiropodist via London's Homeopathic Hospital. As I walked into his Consulting room, his words were, 'You've got an old man's gait.' He altered my orthotics and suggested an orthopaedic surgeon I could consult.

For years, my husband and I had gone cycle touring, until that is the feeling in the soles of my feet on the pedals was no longer comfortable, limiting physical activity to walking, seeing as swimming caused the feet extra tingling once in contact with the water. He was always telling me to pick up my feet as they slid, irritatingly to him, along the ground. The lower legs began to ache after short distance walking and I had got to the stage when our three mile walks through Epping Forest had become too onerous. Hence my urgent need for physiotherapy support.

Once I saw a Neurologist, he arranged for an MRI scan, and this led eventually to a week as an in patient at Old Church Hospital in Romford. A number of other tests, including a lumbar puncture were done, which led, at last, to a diagnosis – spastic paraparesis, after Friedreich's Ataxia had been ruled out. Baclofen was prescribed (2 x 10mg daily, now three) and I was placed on a Consultant neurologist's list for six monthly appointments. Although she recommended levodopa, I appealed to the HSP Group at this stage for their experiences with this drug and decided not to take the suggestion up. May I say that the Internet failed to bring up the existence of this invaluable Group until I discovered, via Google Image, that I had to use the vital letter, 'H', and the rest is history. For me it has been a veritable lifeline in so many ways, for personal morale (or fellowship, as William Morris would have it, calling it 'Heaven') and invaluable information.

I have just returned from another of my monthly physiotherapy sessions, I'd like to share with the readership my own experience

of trying to keep my mobility going as long as possible. What had the NHS to offer me? Feet had clearly been of no interest to my GP. The NHS physiotherapist who was responsible for neurological cases merely provided six weeks of pep talks and then suggested that I have a calliper fitted on my weaker leg. End of story. Disappointed, I managed to locate the helpful physiotherapist who had moved to our local David Lloyd Centre, attracted by the belief he expressed in the early days of our relationship, namely that 'You are never too old to improve.' With my husband's support, I perform the exercises I am given daily (scissor walking is a particular challenge), but we are working on it. I have a rollator for outdoor use, and one indoors. Older Londoners still have Freedom Passes for bus and Tube and there are cabs. There's advice from true professionals. There's supportive and attentive family relationships. And then, there's that vital ingredient: HSP Membership. What's not to like?

Sylvia Ayling Region 5

Dear All,

I have recently been fitted with Dual FES as my walking has somewhat deteriorated lately, weakness is setting in and the dreaded scissor gait is rearing its ugly head.

I was fortunate enough to meet with a local neurophysio who was able to provide me with my first unit (left leg only; considered by me to be my weakest) and I got along fine with it though I hated the wires, a pain when walking, getting caught in clothing and the box? Let's not go there, trying to tuck them away once you've been to the loo...too much information?

My Physio said I should consider dual FES as she thought this wouldn't throw me off balance so much (I have numbness in both lower legs). I agreed and she then explained that due to the complicated nature of funding (yes that old chestnut) I would have to be referred to a large hospital that basically holds the purse strings.

So I wait for an appointment which I eventually get some 2 months later and off I

go on a 90 mile round trip to be assessed for this wonderful bit of kit which I had reliably been informed would be a lovely little digital unit so the number you select for the power to each leg could be set without it 'catching' something, and giving you a nasty little shock: not nice!

Unfortunately this was not the case as I was told by the clinicians that if I want Dual FES than it's still the old fashioned black box brick type thing, a little bigger with the dials that can still catch and deliver that little shock just when your not expecting it (normally in the supermarket or somewhere equally embarrassing.) Or I can stick with one channel and have a nifty little digital number. Could I have 2 digital channels, one for each leg I asked? They are more discreet and I think just by looking at my stick people can assume there is a problem with my walking without me having to advertise the fact with a large bulge just about hanging onto my trousers/skirt. I don't always have such deep pockets to house such a contraption, don't get me wrong I know all things must start somewhere but it's been proved: a digital box has been created, shock horror! Can't do that, they say haven't got funding for that scenario. I had my heart set on having both legs work well together so rather reluctantly agreed to go with the dual "hip flask" as I like to call it when people want to know what it is when it's fallen from the waist band of your trousers for the fourth time that day.

I have used it regularly now but find the wires too much and bloody annoying!

I decided to call Odstock (the suppliers of these units) direct and spoke to a very helpful chap who explained there was no reason at all for me not to have 2 digital channels, one on each leg and that they supply units like this if requested to do so, he suggested a funding issue (here we go..)

I have the most wonderful GP, thank God, who has straight away put an appeal in place for me to have 2 digital channels.

Vain? Conceited, you might say.

If I was obese or a heavy smoker or habitual drug user I would have money being thrown at

me left right and centre in order to get myself back on track. Why, when we have been diagnosed with a long term (ah there it is, this is gonna cost money...long term) progressive, degenerative condition are we treated like second class citizens.

I have to wear the "brick" not the consultant/Physio etc. I want to appear fairly normal physically. Is that too much to ask for? I don't want to appear ungrateful, but is it really too much to ask? I do think FES is a wonderful invention and has benefited a lot of people but we are all very special people with an unusual condition. We deserve better.

Sherrill Casburn Region 8

Hi everyone

Last year the H S P group gave me a grant for a lighter wheelchair, which we both get benefit from as it is better for me to push and for Paul to lift. We would like to thank the group.

Since getting my new wheelchair I have joined a community dance group which does contemporary dance and the lighter chair has enabled me to do this and I have performed in two productions on stage which I enjoyed.

I was interested in dance but never had the chance to take part so I am doing something that I have always wanted to do. Some of the dancers have disabilities and who dance with their carers its hard work but fun.

One of the performances was with a touring group that asks the community to dance with them that was good as we only had ten hours of rehearsal in just three days.

Thank you again to the H S P group for making this possible.

Pattie Raven Chapman Region 11

Challenging my 'inevitable' progression

I was diagnosed in 1996 by the neurologists at the National Hospital in Russell Square, London. I was not offered any treatment and crossed fingers were the only hope given that the deterioration would not be too rapid – I'm sure this is a familiar story for most

members. From that day on I found I would accept my mobility decline as 'my lot' – although I do have regular 'black cloud' days.

That was until I was recommended treatment by a fitness trainer here in the North of England called Paul Hallam. Paul treats many disabled people including daily training for Ben Parkinson – an ex-Afghan soldier and a double amputee. I was first struck by his acute sense of 'how to put things right'. We were battling against 15 years of a slow decline and training was/is hard but mostly exhilarating. The initial sessions included stretching and building muscles that had never been treated before and lay dormant at the hands of the numerous physiotherapists and highly qualified neurologists that I had seen over the years. I don't completely understand where his ability is coming from; a rare gift from a person looking least like an angel (more like a bodyguard/sergeant major) but that's exactly what I feel he is! From the start I felt I could trust Paul 100% which is just as well because he has my legs in the most bizarre positions and guides me through exercises that I didn't realise I'd be capable of doing. I now know far more about my body's efficiency and lack of – it's a very slow process and one in which I can recognise changes in movement but they haven't become visible outwardly yet – I find this aspect pretty frustrating and am realising just how impatient I am.

My sessions are 3x per week, they started in October 2011, with considerable travel to each – I wouldn't waste my time and money if I didn't have such faith in my new 'hobby'. I am pretty obsessed with doing some kind of daily exercise at home between sessions and I can hear Paul's voice in the kitchen telling me to stand correctly as I wash up!

Along with other plusses there is an increasing inner confidence – slowly, as it is. It's such a good feeling to know that my body is starting to work again and not just quietly deteriorating. This is so important because HSP sufferers (and, I'm sure, those suffering all types of disability) think very negatively about the way their bodies behave. Paul seeks to improve the mind and body and treats each

client as a whole person without focusing on the disability.

In his sessions I have walked approx 8 steps unaided – this hasn't been possible to do for almost 2 years. Yesterday in a session, I managed to carry out 10 jumps! Does Joe Bloggs appreciate how complex it is to jump? It makes me wonder if similar intense (and sometimes painful) training had been offered at the time of diagnosis that I'd be at the disabled stage I have reached. I haven't forgotten that I was told that I would progress and I don't know what is possible in the future if I continue but I know that I need more hope than crossed fingers!

Laura Branigan Region 10

Regional news

Region 6

Our last meeting of 2011 was held in the Seabank Hotel Porthcawl, the staff were very helpful letting us use one of the visitor lounges at the front of the hotel with a wonderful view along the sea front. We also had a super buffet laced on for us with more than enough food to go around. Eleven people attended the meeting with a new visitor from Cardiff that Sandra was able to track down from an old newspaper cutting (as of yet she has not joined the group).

We also had two new members from West Wales Gwyn and his wife Petra, it was nice to meet them both. They enjoyed themselves because they have now booked to go to the Ashburton meeting in March which pleased us very much.

I am hoping that the hotel will be able to accommodate us in May this year, they are closed until Feb 14th so I am unable to confirm the date at the moment. As soon as I know I shall post it on the hspwales web site.

Best wishes all and if it's not too late a Happy New Year to you all.

Peter Bateman Region 6 Co-ordinator

Poetry

Moving on Together

The New Year is with us, what will it bring,
Another journey we are set to begin.
I can see this New Year very clear,
This HSP thing I will not fear.

The mind can be vicious, then bring you to tears,
may your heart listen as well as it hears.
Words of hope in the winds I do now hear,
My world a better place, I show no fear.

Let me take this chance to say,
May your year be happy, I will pray.
Moving on together, a team we must be,
Friendship, support & love is the key.

Christine Snow Region 10

Me and HSP

Hi my name is Sandra I have got H.S.P. but please don't worry it's still me,
I know I've got a faulty spine but I can't help it it's still mine.
I know I can't do much walking but it never stops me talking.
So out we go with my wheelchair to see our friends and get fresh air.
Off we go then Pete and me call in the Pavilion for a cup of tea.
Phew now there is no stopping' off we go to do some shopping.
Then it's home to watch TV to see there's plenty worse than me.

Sandy Bateman Region 6

Forthcoming Events:

Region 4 get together

Saturday March 31st 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Region 3 Meeting

Date to be arranged
The Orange Tree, Hitchin. Call Della
Brookman on 01462622946 or
07513004040, or Ian Kitchen on
07540476735

Region 6 (Wales) Meeting

Date to be arranged - See Regional News
Call Peter Bateman on 01656 788502

Afternoon tea Regions 1 & 2

Regions 1 and 2 will be having their Spring
Afternoon Tea on: - Saturday April 21st from
3:00 to 6:00 p.m.

At: - The Clockhouse,
Chapel Lane,
Milford,
Surrey. GU8 5EZ

Contact Jane Bennett on: 020 8853 4089

HSP Support Group AGM

Saturday June 16th 2012
Trident Technology and Business Centre
Leamington Spa

New Members

We welcome the following new members:

Barrie Moss
Shaftsbury
Region 4

Edwin Walton
Bridlington
Region 10

Gail Calvert
Penryn
Region 4

Martin King-Davies
Harpenden
Region 3

Maurice Charge
Hertfordshire
Region 3

If you are interested in contacting any of the new members listed, please contact the relevant area coordinator, or the membership secretary, who can then supply the necessary contact details.

Useful Contacts

	Email	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	bravoechoonovember@btinternet.com	01202 849391
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218184
David Pearce – Exec Committee Member 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
Simon Hubbard – Research co-ordinator	si@sjhubbard.com	01908 508866
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
Della Brookman – Joint Region 3 co-ordinator	Della_brookman@msn.com	01462622946
Ian Kitchen – Joint Region 3 co-ordinator	Ianpk2008@hotmail.co.uk	07540476735
John Moore – Exec Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	john@moore108.orangehome.co.uk	02392 592784
Peter Bateman – Region 6 Co-ordinator (Wales)	sandra@peterbateman.co.uk	01656 788502
Liz Redmond Neurogenetics Nurse	Redmond.liz@uclh.nhs.uk	020 76762115