

HSP Newslink

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

Issue 32 – May 2014

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

Not bad minton...



Confession time! Before the 2012 Paralympics I had never witnessed any disabled people playing sport. In fact other than the regional HSP meet ups I had not met anyone else with a physical disability. I knew that I needed to improve my general fitness, move a little from the Leila size dent on my sofa and actually use my secret but strong competitive streak for something better than sometimes winning

at Trivial Pursuits. I also had no idea for how to find anything interesting and whether I'd be any good as I haven't really done sport since finishing school – this felt scary, particularly as my experience of gyms has generally been terrible and made me feel very conspicuous.

Through a number of coincidences, one of which was being spotted in Wilkinson's trying to dodge a dozy trolley wielding person oblivious to me in my wheelchair by one of the coaches and a good search of the [Parasport club finder](#) by a fitness obsessed friend I discovered my local wheelchair badminton club, The Devon Racqueteers.

I was highly nervous as I went to sports centre of my first coaching session, particularly as the first person I spoke to just happened to mention that she had won the ladies London Wheelchair marathon recently (wow!). However all the players, coaches and observers were incredibly welcoming. The sessions involved warm ups, one to one coaching and then either singles or doubles games. After five months it is still taking me a while to get my head around having to push, hold, hit and move at speed but it is so much fun.

The coaches are excellent and focus on developing your individual skills. Every few weeks we play matches against able bodied teams; this is really good at improving your game because they still have the advantage of height!

In Devon the only thing you need to join is to have some form of mobility impairment and many of the players are not full time wheelchair users. The club has fast sports wheelchairs available to use and spare racquets if needed. The Club was formed in 2008 and is now the largest wheelchair badminton club in the UK. Many members enjoy the social side of meeting together and playing for fun, while others have achieved considerable success winning many gold and silver medals at various national competitions. Four of the players have a parabadminton world ranking. The club recently won Badminton England club of the year.

Now I am very lucky that this club is a 20 minute drive for me. I do not have ambitions to be an elite Paralympian (when it is finally recognised by the Olympic Committee) and am yet to play in a tournament but I am getting regular exercise, better upper body strength, more confidence, becoming less isolated and learning about activities I never thought possible such as disability climbing and fencing. I have only been a member for five months and really appreciate the opportunity socialising with people who are also dealing with 'stuff', who all walk a bit weird and who are a supportive bunch.

As a previously not bothered about sport person (because it was hard) I am happily surprised about how much I enjoy playing badminton. My competitive streak is now not so secret and focused on playing better and my sofa is at least having an occasional rest. I know that I am biased towards wheelchair badminton being the best option; check <http://www.ebad.org.uk/index.php/clubs> for local clubs but other sports include archery, rowing, basket ball and curling. I

just really recommend seeing what disability sport is available near you. The simplest way is though The Parasport club finder <http://parasport.org.uk/find-a-sport> which has a clever system where by entering your impairment, your town or city and the sports you are interested in, the tool brings up a list of suitable clubs to contact. To get all Nike on you just do it!

I'm a member of the HSP Unite Facebook page so feel free to ask any questions.

Leila Manion Region 4

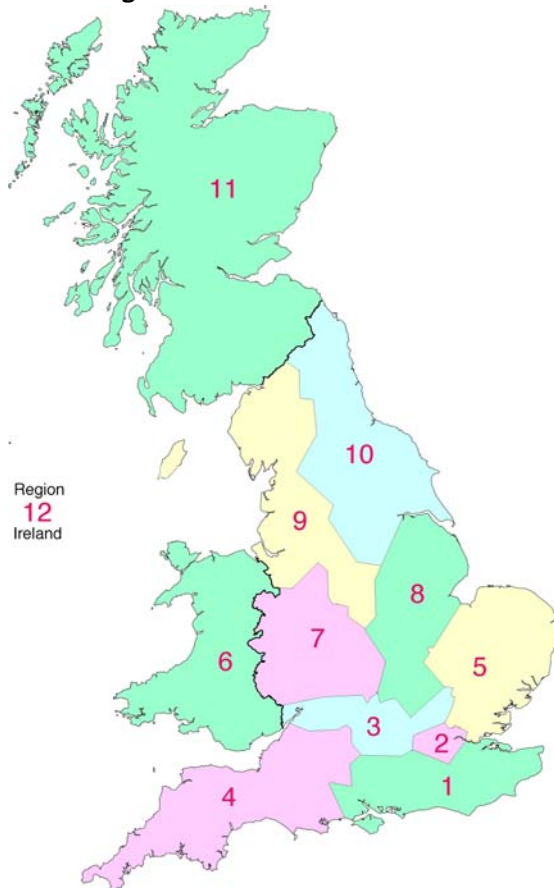
Chairman's Column

As I mentioned in the previous issue, I have recently acquired a new scooter which I'm delighted with. It is a Drive Cobra which is a class 3 scooter meaning I can use it on roads (it is taxed and registered with DVLA). I've been regularly using it to go into town or to the local pub and I'm still very happy with it. In fact I'm now considering not renewing my motability car when the lease expires in June 2015. The scooter (and my free bus pass) allows me to go anywhere locally and the extra cash would certainly be very useful. This decision could be made easier by the fact that there are three other cars in my household.

Following the last newsletter where I mentioned I'd been using a vibration plate, I'm pleased to have heard that at least two other members have followed suit. I'm still using mine on a regular basis although I kept off it for a month after straining my calf muscle. You'll read more on vibration plates in Eileen's letter, later in this issue.

The improved Spring weather has enabled me to increase the time I spend working in my garden. Some days I spend more hours outside than I do inside. I find my garden very challenging at times but as some of you know, it gives me huge pleasure and I find it great therapy. I would recommend this therapy to anyone, raised beds are the secret. When I'm having what I call a 'fatigue day', I enjoy reclining in the sunshine by the pond. It gives me immense

satisfaction to look at what is usually a tidy, well maintained garden in the knowledge that I'm responsible for the lovely view. A couple of members have recently enquired where all the HSP Regions are. They see a letter from a member in a numbered region and have no idea where they're from. The map below shows where all our regions are located.



At recent HSP meetings in Ashburton and Milford, members have been discussing and asking questions about PIP (Personal Independence Payment). From now until 2018, the DWP will replace our Disability Living Allowance with PIP. This only affects those of us who are between 16 and 65. We'll have to reapply for PIP and this will probably mean attending an assessment. I don't know what the assessment will entail but my advice is to ensure you prepare yourself as thoroughly as possible. By this I mean taking along a folder of supporting documentation, such as letters from consultants, physiotherapists, occupational therapists etc. List all your symptoms and drugs and don't cut any corners. Nothing

is insignificant. I don't want to scare anyone about this, in fact I believe that genuine cases such as individuals with HSP won't have problems in being awarded PIP. Members who currently have a lifetime award of DLA won't be assessed for PIP until October 2015 at the very earliest. If anyone is unsuccessful I would strongly recommend they appeal but let's hope that none of us have to go through with this. It would be useful to hear from members who have PIP assessments so that others can benefit from their experiences.

I've been busy organising the AGM which takes place on June 21st and you'll notice that the agenda is included in this Newsletter. We're experimenting with the date and seeing if avoiding Fathers Day may give us a higher attendance.

You'll notice that the AGM begins with the necessary formalities where we elect new committee members and discuss the accounts. Please consider joining the committee if you feel you have something to offer. I believe that new people are needed for any organisation to improve and move forward and our committee hasn't seen many changes for the last few years. In fact, if anyone feels they could step in as Chairman, please put your name forward. I'm not disappearing anywhere but I'd like to reduce my workload a little as I certainly don't have the energy I had a few years ago. I'm more than happy to remain as Membership Secretary and Newsletter Editor and I'll certainly stay on board for another year if nobody comes forward.

I can't close without congratulating Sherrill Casburn who is the latest of several of our members to be awarded a flying scholarship from FSDP. Sherrill will be learning to fly a microlight at Old Sarum airfield on the outskirts of Salisbury later this year.

Thank you to those of you who've provided articles and information for this issue. Any letters or articles are always much appreciated as it is largely the input from members that makes the Newslink such an interesting read. I certainly can't do it without your help. Particular thanks to

Adam Lawrence for his column which will now be a regular feature within the Newsletter. Following Adam’s first article in the January issue I received plenty of positive feedback from members who found his column very interesting and informative. I look forward to meeting up with members at forthcoming events and I’m always on the end of the phone if required.

Ian Bennett

Research Column

For this column I’m reporting some aspects of the on-line survey I mentioned in the autumn of 2013. I published the results on my blog, and people are welcome to read the full set there:

<http://hspjourney.blogspot.co.uk/2014/02/hsp-survey-results.html>

There were 121 respondents who completed the survey, predominantly from the USA and the UK, but also Europe, Canada, Australia, India and South Africa.

Symptoms Analysis

I found 13 symptoms which occur often in descriptions of HSP and asked respondents if these symptoms were an issue for them or not. For each symptom respondents selected the most appropriate from a list of choices, which I have grouped into severity bands;

Severity	Severity Band
Do not have	-
Occasional symptom	Minor
Minor symptom	Minor
Frequent symptom	Significant, Moderate
Regular symptom	Significant, Moderate
Most of the time	Significant, Major
All of the time	Significant, Major

The table overleaf shows the percentage of respondents with each of the symptoms, ordered by frequency – the most frequently occurring severe symptoms at the top.

This shows that the two symptoms which affect people the most are loss of balance and getting stiffer when it is cold, which is a significant issue for 70% of respondents, and an issue for more than 95% of respondents. Fatigue affects more than 90% of respondents and is a significant issue for more than 60%.

Bladder problems, stress and back pain affect around 80% of respondents, significantly in about half of those. Clonus, numbness and depression affect around 70% of respondents, and show a similar pattern where half of those affected are significantly so.

Bowel problems and loss of vibration sensitivity affect around 60% of respondents. These symptoms appear to be significant for a smaller proportion of respondents. Pes cavus and hammer toes affect the smallest proportion of respondents, around 50%, and these symptoms appear to be significant for a greater proportion of respondents.

Analysis of Symptoms against Mobility

For a more detailed analysis I grouped the respondents into groups according to mobility;

Number of Symptoms – walking unaided

Those who can walk unaided tend to have 4-5 minor symptoms, up to three moderate symptoms and no major symptoms. All respondents in this group had at least three symptoms, at least two of which were minor.

Minor symptoms are likely to include Loss of Balance, Stiffness in the Cold and Fatigue, and may include Bladder problems, Stress, Back Pain, Clonus, Numbness or Bowel problems. Moderate or major problems may include Stiffness in the Cold, Fatigue, Stress, Back Pain, Clonus or Numbness.

Number of Symptoms – use aids some of the time

Those who use mobility aids some of the time tend to have 4-5 minor symptoms, up to three moderate symptoms and up to one major symptom. All of the respondents in this group had at least five symptoms, at least one of which was minor.

Minor symptoms are likely to include Loss of Balance, Stiffness in the Cold and Fatigue, and may include Bladder problems, Stress, Back Pain, Clonus, Numbness or Bowel problems. Moderate or major problems may include Stiffness in the Cold, Fatigue, Stress, Back Pain, Clonus or Numbness.

Number of Symptoms – using mobility aids all or most of the time

Those who can walk using sticks all or most of the time tend to have 2-5 minor symptoms, up to 5 moderate symptoms and up to 5 major symptoms. All of the respondents in this group had at least 7 symptoms.

Minor symptoms may include Bladder problems, Stress, Back Pain, Clonus, Numbness, Depression, Bowel Problems and loss of vibration sensitivity in the legs. Moderate or major problems may include

Loss of Balance, Stiffness in the Cold, Bladder problems, Stress, Depression, Bowel Problems, Pes Cavus or Hammer Toes.

Symptom	Do not have %	Minor %	Significant %
Loss of balance	4	26	70
More stiff in the cold	4	29	67
Fatigue	8	30	62
Bladder problems	18	39	43
Stress	19	42	39
Back pain	22	42	36
Clonus (jumping feet)	30	37	34
Numbness	31	36	33
Depression	34	34	32
Bowel problems	39	36	25
Loss of vibration sensitivity in legs	39	37	24
Pes cavus	48	15	38
Hammer toes	53	18	28

Adam Lawrence

Useful Information

Hereditary Spastic Paraplegia's Unite

This is a private group on Facebook, to encourage people affected by HSP to share information, offer advice, chat and socialise. I'm an administrator for this site, along with Lorraine Saupé and Debbie Best.

To date we have 462 members. We have many members from all over the UK, along with USA, Canada and Australia, to name but a few.

This group has brought many people together, to chat about HSP and living with HSP. The main thing is, that people realise that although HSP is a rare condition, they are not alone and that there are other people out there that understand HSP and can empathise with the symptoms, feelings of depression and all that it brings into our lives. The caring nature of our group is not just for the negative side of HSP, but also, for sharing news about research, our experiences and encouraging each other in their daily lives. Giving advice, based on each individuals journey through HSP. i.e. Occupational therapy, Physiotherapists, Neurologists, AFO's (Ankle, foot orthotics

or splints). Giving sympathy and encouragement in whatever any individual is feeling\going through, at any one time.

Saying this, there has been many a friendship made on "Unite", as I like to call it. :) There is humour and jollity at times, where a member has accounted their experiences, with a bright, positive attitude and receives, thanks for brightening one's day. :) It is not all doom and gloom I am happy to say. :)

As said, this is a PRIVATE group, which is controlled by all of the administrators. We try to keep it safe for our members in the way of weeding out those that might be trying to sell items that can (cure) HSP, or other items to make money for themselves. Our members are not pestered for money etc, this includes posts asking for donations etc. We have zero tolerance with this and such posts are removed, as is anyone who is deemed to have a detrimental effect on our site.

So no need to worry about being on the internet. You can join Facebook, just for HSP Unite. No need to add friends, unless you want to. There are also, privacy options, to limit any unwanted attention. I have been on Unite for many years and find it indispensable.

<https://www.facebook.com/groups/19469684343/>

This is the link to Unite, if you are interested in having a look and joining us. You can, just go onto Facebook, type in Hereditary Spastic Paraplegia's Unite, in the search bar and request to join.

We would love to welcome you all to Unite.

Della Brookman Region 3

HSP Group Funds

The HSP Support Group is now in a position to support research projects with a maximum grant of £10 000. Applications for such support are welcome. Please apply in writing.

Grants are also 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 is currently £500. If interested, please request a grant application form from a committee member.

Members' Letters

Dear Ian,

Thank you for your email last November advising of the genomics England project, and which also was highlighted in the last issue of HSP Newslink. I sent emails to Prof Houlden and Arianna Tucci and was found to be a good candidate for the sequencing, as I am also an outpatient with the National Hospital under Prof Nick Wood, and after a number of emails with Arianna and telephone contact blood samples were provided in December by my Brother, Sister and me.

My annual appointment at the National Hospital fell during February and although I would usually see Nick, on this occasion I actually saw Prof Houlden and Arianna Tucci and after the consultation they said they were very much looking forward to the results which could take between 8-12 months. They are also involved with other rare conditions besides HSP.

For my own story my health changed in 1976, aged 21/22, and I was immediately referred to the National Hospital neurology department before moving to the genetic clinic under Nick Wood about 10/12 years ago. I have no known relatives with HSP and my condition has slowly worsened over this long period and in line with other sufferers. So I am hoping that the outcome of the sequencing will finally confirm the gene/s and that this leads with other results to finding a solution sooner rather than later. I certainly didn't expect all those years ago that we would be where we are now with research in my lifetime.

With regard to the HSP website I was amazed by how much it has evolved as I had not looked at it for quite a while. From my first contact with the group, which coincided with my transfer to Nick Woods' clinic, I have been very impressed with how it is run and the information available and this continues to be so today. Well done and thank you HSP Group and congratulations on reaching 25 years.

I recently received a demonstration from Luggies and Monarch with the view that we are due to take some overseas trips shortly and the need for electric wheels is very much on the cards. Both of these models fold up to about 17 inches by 17 inches by 17 inches and weigh about 50 pounds. After consideration I bought the 'Mobie' from Monarch much to the relief of my wife and some HSP friends who meet at Milford, Regions 1 & 2 who have been on at me for some time to buy some wheels. Hi Carol (aka Sylvia)!

John Patching, Tiptree, Region 5

Dear Ian,

During my last visit to Plymouth University I discussed with Amanda my need to go on a diet and the fact that disabled are not able to perform certain exercises, so what do we do?. Several weeks later I made a visit to my doctor and made the same comments. My doctor informed me about activities with Cornwall Healthy eating, which includes exercises for all abilities. The group cover the whole of Cornwall and I was very lucky in as much as the next course which started on the 25th September was to be in Truro.

Well I'd signed up for it so thought I'd better go. Tracy and Mary who run these courses are very good and very easy to talk to. It starts off with everyone being measured height wise, asked your age, waist measured and weighed!! Unless cooking was done (which it was on two occasions), the first half of each evening was spent talking about food in general and the good and bad values of it, especially what

diseases we thought eating too much of the bad food like fat and sugar did to us and our bodies. We were also reminded of the size plate we should put our food on, but at no time did they lecture us on these facts we joined in discussed every thing and listened to comments that anyone was willing to make.

The second half was the exercise section and although I had great difficulties with the first couple of weeks, things improved. We started off with walking and stretching to warm up and then did exercises around the room with a cool down of walking at the end. This was all done to music and a lot of laughter. Some of it being caused by me because if we were stretching, then so was my stick! I did enjoy it and with a little adjustment of how each exercise was done, I managed them all, but I must say at this point that I was very lucky as for this group of 12 weeks they had a volunteer with them who came round with me and encouraged and helped me. Eileen was fantastic. This doesn't end at the end of the 12 weeks as they make appointments again to talk and weigh you. The scales don't just weigh you, but tell you your fat content against muscle, which as you lose weight should read a better percentage of muscle to fat. It would take a long time to praise them enough. It was all constructive criticism and advise, plus they were always open to questions for advise. Also I'm told that if you have any mobility/disability problems you are more than welcome to bring a helper of your own.

Cornwall can't be the only County to do this but for people in Cornwall either speak to your doctor or you can go on line at www.cornwallhealthyweight.org.uk

At the last meeting I had with Tracy and Mary I told them that there was a new Zumba, Zumba Gold which can be done in a chair which the ladies are very interested in, so if anyone can help further I would be very interested.

Jennifer Gill Region 4

Norwegian Cruise

As we have not had a holiday for about five years, we could not resist the temptation when a discounted cruise came up. We have never been on a cruise before, so were not too sure what to expect. We booked with Cruise and Maritime and later read some of the not so good reviews on the internet. Oh, oh, what have we let ourselves in for?

Our cruise went from Hull to Rosyth (Edinburgh), Shetland Islands, Bergen and the Fjords. The boat MV Discovery (was in the "Love Boat", an American TV sitcom in the 1970 ties) and is relatively small, having room for "only" 700 passengers.

The boarding at Hull was well organised, with no queuing and all heavy cases were delivered to the cabin by staff. I took my travel wheelchair, which does require another person to push it, but only weighs 10kg and I was allocated a disabled cabin, which is twice the size of a normal standard cabin. The shower in the wet room was magical, with a soft padded seat that one could almost lie on. It also had a shower head "parking unit", so that one would not need to get up and down to rest the shower head while getting on with other tasks. I am definitely getting one for my bathroom at home.



Our Cruise ship The MV Discovery

On board there were a few people using wheelchairs and quite a lot using rollators. Getting about was not a problem. We have been told that the average age of a cruiser is over 60, but the age group on this cruise ranged from 30+ to 80+. People were very friendly, helpful, chatty and generally good company. The crew were from

Ukraine, Romania, Bulgaria, Goa, Sri Lanka, Malaysia and elsewhere. All spoke good English, good enough to have a joke with and worked extremely hard. They could not have done more.

Food was excellent and there was far too much of it. The evening meal had 8 courses if one wanted it all. The evening meal was served, so there was no buffet style having to carry food about. Breakfast and lunch was buffet, but there were always people and staff willing to help, if necessary.

When in port, one could go on trips or disembark and do one's own thing. We did a mixture of the two and I even managed to get in and out of a tender boat! In the Shetlands, we saw the murder scene (in the Shetland BBC TV crime drama) and learnt that Shetlands have 100 islands of which only 16 are inhabited. They don't distil whisky, speak or learn gaelic or wear kilts. In Flam we climbed (on a train!) 900m above sea level and had a metre of snow there. We were due to dock in Odda in the Fjords, but as it was Good Friday everything was closed even most of the port, so we had to use the ship's lifeboats to disembark, which was an adventure.

We liked the whole experience very much and could not really understand some of the comments on the internet. We would definitely recommend this cruise, for the interesting places visited, the way the whole ship is efficiently run and the size of the ship. Most new cruise ships take 2000 – 3000 passengers.

Irena Pritchard Region 9

Dear all

Ireland, Breanor, the nest from which I learned to fly. A loving farmhouse surrounded by trees and fields. It stood on the sunny side of a sloping hill and at the end of the river which meandered its way through golden gorse and disappeared under a stone bridge into the woods and beyond.

My parents were a blend of opposites. My mother was kind, patient and gentle with

far seeing wisdom, and she only expected the best from her fellow human beings. One of life's angels. My father was a man with a high level of intelligence but a threshold of tolerance, patience was not a virtue he had grasped. He loved nature especially his farm and all its animals. With his parents and two old gentlemen living under the same roof his 5 children were reared strictly. I was not treated any differently because of my disability which I believe helped me to strengthen my muscles, my arms and back which are still strong today.

Nature was a great educator giving free reign to our imaginations, with no form of transport other than a bicycle we relied on them to get from A to B which meant we had to negotiate some steep hills and this was always a brilliant challenge to see who would get to the top first if at all. The memories of this still make me smile today.

For me it was early onset of HSP as it is with our daughter Kathleen trying to give a positive outlook and keeping this going each day and to show her that everything is possible is what I try to portray to her and the rest of my extended family, and that, I am not ready to stop yet.

After reading our last newsletter, Ian Bennett mentioned how he and his family had used a vibration plate; he also mentioned how it helped him with the circulation in his legs that meant that they were not as cold. So I hit gumtree and secured myself a vibration plate for £25, at first I used it in the evening for 10 minutes but I realized that I made the muscles in my legs over active at night so I contacted my physiotherapist and started working on the idea of using a bicycle again like I did regularly as a child. I used the vibration plate in the morning for 10 minutes and then I hire a power-assisted tricycle and cycle in the local park. To start with, you may need more assistance but I find that I try to challenge myself against the tricycle and go a little distance on my own. It is very hard but that is what makes it feel so

good when you finish a distance. As a child, I would cycle up the highest hill. Who would win me or the hill? The feeling is so brilliant when you succeed. There are many challenges in life and HSP is one of those. On the farm we had to milk the cows each evening after school and on the following day we removed the cream and it was put into the butter churns, we had two of these, a hand one which sat on a table and could be worked by one person and the second, a barrel churn which stood on its own stand and required the two of us, it took my brother Johnjoe and I to work it. After a certain amount of churning, the thick cream formed into lumps of butter. The faster we could achieve this the better the butter and this was the source of the saying that "long churning makes bad butter" then we salted the butter and what was left in the barrels was buttermilk and the farmhands loved this especially in the summer after spending long days on the land, and my mother would use it to make an endless supply of fresh bread.



The reason I explain this to you is let you know it is not going to be easy; it's all to do with motivating yourself. I wanted to do something to help my muscles and prevent HSP taking over. Now I know that I cannot stop this from happening I will always have a picture of my beautiful mother not knowing about HSP and her fight. So I will keep these legs moving, each day I will get up, set myself a challenge 10 minutes on the vibration plate and 1 hour in the park

on a tricycle two days a week to start and build on this through the summer months. It's not going to be easy but this is where my childhood and the work which my parents set for us each day helps. You must get up off your tush, try to get something into your head which will, keep you going, yes it will be hard but you are doing something for yourself and this will benefit you, and you will be the one with that big smile on your face. Just don't quit. I have times when I just want to stop and get upset finding it impossible, finding something to get me back on track can be very hard, but Eileen does not quit easily, and I will always find a way to smile.

The vibration plate is a super idea and if you look up pedal power, different towns will use different names but these can be found from your local council's website. Your physiotherapist will also have this information. You can use power assisted tricycles to start and they have clamps for your feet to hold them in place. The people who run the groups are so kind you will feel at home very easily. There is always a way to keep fit you can even call it exercise for your heart and get it pumping harder and you will feel splendid. Try it once and I bet you will love it!

Eileen McCarrick Region 6

Regional News

Region 9

St. Helens – North West group meeting

We met at the St. Helens South Premier Inn (Eurolink, Lea Green, St. Helens, Merseyside WA9 4TT) on Saturday 29th March in the afternoon (2 – 5 pm). This Premier Inn has a lovely meeting room, wheelchair accessible, free parking and is attached to a Brewers Inn restaurant. Lunch, snacks etc. are available and we do get tea and coffee included.

We had a lovely afternoon, chatting about things that help us, PIPs, medicines, holidays and looking forward to the AGM.

We welcomed a new young member, Ian, who with his positive attitude and many jokes, made us all laugh.

This was the first time that Ian Bennett and John Mason did not come. It is a long way for them and we need to stand on our own feet now. We also missed a few members who could not come due to injuries and we wish them speedy recovery.

We can organise our group as we wish. It would be good for members to share ideas about what they would like to see the group do. Should we go out somewhere once a year? Just for fun or see something that interests us, connects us? Should we have speakers? Should we book a room and stay overnight? Any other ideas? Perhaps we could use the Facebook pages to share ideas?

We are planning on having the next meeting towards the end of October and are looking forward to meeting you all.

Irena Pritchard Region 9

Forthcoming Events:

Region 4 get together

Saturday October 18th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on: 01202 849 391

HSP Support Group AGM

Saturday June 21st
Trident Technology and Business Centre
Leamington Spa, CV34 6SW

Afternoon tea Regions 1 & 2

Sunday November 23rd 3pm – 6pm
The Clockhouse Milford
Speaker from the local Citizens Advice Bureau to explain / discuss PIP
Call Jane Bennett on: 020 8853 4089

Region 3 Meeting

August 16th 2014 1.30pm – 4.30pm
The Orange Tree Public House
100 Stevenage Rd, Hitchin, SG4 9DR
Contact Della Brookman: 07710 637 941
or Ian Kitchen: 07540 476 735

New Members

We welcome the following new members

Janet Boffey
Trowbridge
Region 4

Marie Davis
London
Region 2

Paul Rose
Warwick
Region 7

Kay Freeman
Kingsbridge
Region 4

June Masding
Birmingham
Region 7

Mrs Susan Rowe
Brixham
Region 4

Linda Stone
Brendon
Region 3

If you are interested in contacting the new members listed, please contact the relevant area co-ordinator, or the membership secretary, who can then supply the necessary contact details

HSP Support Group 2014 AGM Details

Saturday 21st June

The Trident Technology and Business Park, Poseidon Way, Warwick, CV34 6SW

- 10.00 Coffee & Welcome.
 - 10.30 AGM
 - 11.00 Plymouth University
 - 11.45 Break
 - 12.00 Dr Evan Reid - HSP research- where have we come from and where are we going?
 - 1.00 Lunch
 - 2.15 David Heard - The Sportability Experience - taking the 'dis' out of disability
 - 3.30 Coffee and open forum
 - 4.30 Close
-

Useful Contacts

	Email	Telephone No:
Ian Bennett - Chairman 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechoonovember@btinternet.com	01202 849 391
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John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218 184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	bravoechoonovember@btinternet.com	01202 849 391
Simon Hubbard – Research co-ordinator	si@sjhubbard.com	01908 508 866
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 8853 4089
Della Brookman – Joint Region 3 co-ordinator	Della_brookman@msn.com	07710 637 941
Ian Kitchen – Joint Region 3 co-ordinator	Ianpk2008@hotmail.co.uk	07540 476 735
John Moore – Exec Committee Member 66 Drift Road, Clanfield, Waterlooville, Hants, PO8 0NX	johnmoore.9@btinternet.com	02392 592784
Peter Bateman – Region 6 Co-ordinator (Wales)	sandra@peterbateman.co.uk	01656 788502
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