



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

Carrie takes to the sky



I have always enjoyed flying, when flying on holidays I am like a little kid. I get excited for the take off as well as the landing.

Back in 2005 after Ian Bennett came back from his time at 43 Air School, South Africa (Flying Scholarship for the Disabled) he said that I should apply as I would really enjoy it.

To think of how my life has changed since then.

I applied for 2006 and was turned down as my letter was not emotional enough. Emotion is not a feeling that I talk about. I applied again for 2007, it was hard writing my feelings down but it seemed to have worked, I got a call from Sue and was asked if I would like to attend the selection process at RAF in Cranwell.

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It is quite hard to explain the few days at Cranwell. There were 23 candidates of all disabilities. Over the next few days we had interviews, aptitude tests and a full medical. It was amazing to watch how the thought of being disabled seemed to disappear while we spent the time together.

I can remember leaving Cranwell with my heart beating at a hundred miles an hour and a big smile on my face.

I had this feeling while I was there that I would probably not get the full scholarship to SA as I am originally from SA.

Stupid thought.

When I received the phone call from Sue to tell me that I had received the full scholarship to SA I wanted to cry with happiness.

As the time came closer it was sinking in that I was going to learn how to fly a light aircraft in South Africa.

The time had come and all five of us, Ian Wilson, Jayne McCormick, Alex Krol, Matthew Bishop and I set off from Heathrow not knowing what lay ahead.

The staff at all the airports were very helpful.

The journey was long, sat next to Alex and got to know him more. Once we arrived at Johannesburg they allowed us up to the cockpit of our Boeing 747, what an amazing opportunity.

We arrived at the air school in Port Alfred on the Sunday afternoon and got shown our rooms. Following a very good nights sleep we were up early to get shown where everything was.

All the staff at 43 Air School were all so friendly and helpful and we were continually made to feel very welcome.

We were shown where Flight Operations (Ops), planes and Ground School were. When we got to Ground School we were shown our desks which had a huge pile of books and many other things, looked rather daunting. We were also in a class of 40 students the biggest class that they have ever had.

We were told that for the first two weeks Ground School would be from 10am to 3:30pm quite a long day.

Since the five of us were only here for six weeks we were allowed to fly during Ground School.

Enough about the Ground School, on to the flying.

We had an introduction flight which was amazing, had a good instructor, once we landed I realised that there was going to be a lot of learning, Ground School as well as in the aircraft.

I achieved a lot in the six weeks that I was there. There were certain things that will always stick in my head, especially entering back into the slipstream after a 360° turn.

I am happy to say that my confidence did grow a lot over the weeks I had many ups and down during the time that I was there, had to learn that everyone makes mistakes even the professional pilots.

I managed to fit in 45 hrs flying, you would think that being in South Africa the sun shines all the time, well with days off due to gale force winds, thunder, lightning, hail and rain it was great to get the hours in, can remember in my last week, my instructor and I went up, I thought the clouds were really low, but my instructor flew through the clouds to a clearer spot so we could practice stalls, incipient spins and steep turns. I had three instructors while I was there, might have helped if I had had one, but I learned different things from each of them.

The navigations were the best, spending roughly two hours in the plane flying to national airports, while flying to Cookhouse, 4500ft above sea level, my instructor said that I could take my hands off the control column, it felt weird but the plane flew itself and I could have a look at the lovely scenery.

The five of us got on very well together evenings in the pub and many good laughs. Some of the instructors planned a morning out where the five of us would fly the planes with instructors to Port St Johns which is an airstrip on the top of a high cliff, it was great

with all five planes in a row, scenery was stunning.



Airborne over the coast of the beautiful Eastern Cape

I tried for my solo flight the day before leaving, but no luck, I thought of staying another week to accomplish it, but I thought I had done my time in SA.

Here I come England.

After spending six amazing weeks learning to fly a light aircraft there is no way that I could not carry on and obtain my PPL in the UK.

Want to thank all at FSD for the experience that I have had and will never forget.

The six week experience was very eventful, especially to the great friends that I have made.

Caroline Begg Region 1

Chairs column

Hello everyone

What with the credit crunch and the snow I'm desperately seeking out my fast forward button. I have to say both these situations seem to have drawn together friends, neighbours and volunteering colleagues in mutual support activities. In some way just how we operate.

So first of all let me thank David Harris and his team of helpers for looking after the AGM last year. I have not felt well for some time and was very much hoping for a small window of wellness enabling me to attend. This was not the case, the drive to Warwick was impossible and David very kindly filled in at the last minute. Very common in middle

aged men is the enlargement of the prostate. Fortunately this has enabled us to deal with a minimal cancerous growth very early.

However, intensive treatment over the next 4/5 months is likely to limit my activities in terms of HSP but most certainly to permanently suppress any future development of the cancer. I have a friend who had this treatment some 12 years ago.

This naturally brings me to my next point. I have been involved with the group now for about 10 years. I think it is fair to say we are financially secure and have the right people in the right places to ensure a positive future. Best of all we continue to care and share our good and bad times. I see the increasing use of our chat line and it may well be there are those of you who have the time, skills and enthusiasm to bring some new blood to the top table. Please feel free to talk this through with any committee member.

Echoing on our financial security we have in hand finances to support research activities. We have to consider moving this onto a much larger level perhaps by engaging a professional fund raiser. Perhaps this could be our next project.

Lastly I must thank all of you who have offered your support and encouragement over recent times. As usual please feel free to contact me as you wish.

David Pearce

Editor's comments

I hope you enjoy this issue of the newsletter. Thank you to everyone who has contributed. I'm sure you'll agree that there is some very interesting content, so please keep up the good work for future issues.

I'm very aware that aviation often seems to be a major topic within the HSP Newsletter, but I'm sure you'll agree that some interesting things have been happening in this area that are strongly connected to HSP.

A major example of this was a record breaking event that took place on September 6th 2008. 36 wheelchair users towed a DHL Boeing 757 a distance of 100 metres along

the runway at Lasham airfield using only muscle power and sheer brute strength. What hasn't been mentioned very much, and a fact I'm very proud of is that the highest represented disability involved in this event was HSP. In fact six of the 36 wheelchairs were occupied by people with HSP.

Thank you to Lorraine Saupe, Paul Saupe, Brian Day, David Britton and Ian Smith for the grit and determination you displayed on the day. These efforts have now been officially recognised by the Guinness Book of Records.



Still on the subject of aviation, please note in the "Forthcoming Events" section, that I have now finally managed to organise an HSP flying day at Lasham. Places for this are limited so please contact me very promptly if you are interested in participating in this event.

I must say thank you to Peter and Sandra Bateman who are relatively new members from Region 6 (Wales). They have taken the trouble to attend a couple of recent Region 4 meetings in Devon, and have now volunteered to take on the role as Region 6 co-ordinator. Isabell Quinlan has made efforts in this area up to now, but living in West Wales, very isolated from other Welsh members, organising get-togethers has proven impractical for her. Further thanks are transmitted to Isabell for her past efforts and support.

Although I will endeavour to do so I can't guarantee to release another Newslink prior to our AGM in June. In case this doesn't happen, details of this year's AGM at Leamington Spa on June 20th are shown on page 14.

Secretary's Spot

Since our last issue there have been quite a few different meetings – the regular ones at Ashburton and Milford (unavoidably both on the same date in November). A couple of weeks before this there was a meeting attended by about 30 members at Ewood Park, Blackburn arranged by John Morris and his family. We've also had the Focus Group Meetings in Ashburton. Our hope is that now we'll be able to continue this pattern and have meetings taking place close enough for most members to be able to meet and chat at least once a year without having too far to travel.

Our grant from Plymouth University is being put into effect, we have had a meeting of the focus groups and the results are now being drawn together – we expect a paper explaining the findings to be published in the summer.

We have now put into effect the change of name resolution agreed at the AGM. We are now formally "The Hereditary Spastic Paraplegia Support Group". This is the name recorded with the Charity Commission and on our Bank Accounts. We are updating stationery, forms and posters to reflect the new name – if you spot anything being published with the old details please draw it to our attention.

We have not had much information about items in the Information Booklet which are out-of-date or need changing, so we may well not be producing an update in the near future. We will update when we are aware of enough changes to make a change worthwhile.

Do please get out your pen (or keypad) and let us know of any information you come across – our members are always our best source of information.

Dave Harris

Our help requested

I have received a request from a student working towards an Occupational Therapy qualification.

As part of the course work the student is researching opinions from people with physical disabilities. Participants need to have a physical disability and be over 18 years of age. A written questionnaire will be sent out by mail.

Questions will be asked about the terms used by the occupational therapy practitioners when talking with users of their services. If you would like to help by receiving the questionnaire and completing it then please contact me (contact details on page ##).

I will then arrange for a list of volunteers and their addresses to be sent back to the student.

Dave Harris

Useful Information

Coeliac Disease

I'm aware of three HSP group members who have coeliac disease and many more who complain of irritable bowel syndrome. This is possibly coincidence, but it maybe that there is a connection between CD and certain types of HSP. CD actually affects 1 in every 100 people, but I find it strange that the only three cases I have ever come across all have HSP.

Coeliac disease (CD) develops when our body cannot tolerate gluten, a protein found in wheat and some other cereals, but because its symptoms are often very vague, it can take years to be diagnosed correctly.

Recognising symptoms

One of the problems with CD is that its symptoms are often non specific. For instance, they may mimic irritable bowel syndrome, so you'll get bloating, tummy pains, nausea, diarrhoea or constipation. Tiredness, weight loss, mouth ulcers, and iron deficiency anaemia are also common, and if you have CD, then these are due to poor food absorption.

Another symptom can be an itchy, patchy rash that can appear anywhere on the body, and this can occasionally occur without any other typical CD symptoms. A small biopsy

of the rash will help identify that it is due to CD.

Diagnosis

Individuals with CD usually have low iron levels in their blood. Your GP can carry out blood tests for this which will also check for other CD characteristics. If the results show that you have CD, you'll probably be referred to a gastroenterologist for further tests.

What's next?

CD is a lifelong condition and the treatment is simple – avoid gluten. Once you've taken this on board, the main problem is establishing which foods contain gluten. This sounds simple, but isn't always that obvious. It would be advisable to see a dietician to find out exactly what foods to avoid, whilst maintaining a well balanced diet.

It can take months or even years on a gluten free diet for the effects of CD to disappear fully.

Rice, potato, corn (maize), plain meat, fish, eggs, cheese, milk, most yoghurts, fruits, vegetables and pulses are all gluten free foods.

For more information, visit www.coeliac.co.uk

Thank you to Carol Jakeman (Region 7) for providing this very interesting information.

Wheelchair – No Way!

Has this ever been you?-

HSP slowly takes an increasing toll; things get slower and more difficult. With that ever determined spirit you adapt by finding different ways to do things or indeed ways of not needing to do some of them at all. Then, someone (maybe friend, maybe family, maybe professional) asks the well intentioned question 'do you think that a wheelchair might be useful?' Maybe your answer would be the same as mine - 'NO NOT ME!' You don't elaborate but on your mind are any of the following, plus a few more:

- I can still walk – wheelchairs are for people who can't walk
- I can't walk far but I use the car instead and park nice and close
- It will surely have a bad affect on my work
- I don't need to go shopping – I can do it online
- They look horrible – I don't want to be seen in one
- They're really difficult to manoeuvre and uncomfortable
- I'm not useless

It was certainly me..... I suspect I'm not the only one and I know there's a longer list of reasons!!

It seems daft now, but what I couldn't / wouldn't see was the reality. My way of coping was that I increasingly avoided going to places, and doing things that I often enjoyed. It sometimes also meant that I simply got left out of things too.

With much persuasion, and an awful lot of trepidation I did agree to a 'wheelchair assessment' at my local NHS Mobility Centre.

In direct contradiction to many of my reasons for not having one, I quickly began to realise that the chairs I tried weren't uncomfortable, their manoeuvrability was much better than my own, and to show my vanity, there were a lot that looked pretty cool too!! In a nutshell, I was quickly coming around to the realisation that notwithstanding my reasons for not wanting one, this could be a useful tool – and I'd only need to use it when I needed.

After taking delivery (a pretty snazzy Quickie GPV) a few more things became very clear:

- People I knew didn't bat an eyelid. Why hadn't I done it before?!
- There are lots of great places that you just can't take the car – and now I could go to a lot of them
- I could join in much better with family, friends, and work

- Watch my kids doing those out door growing up things, and not just from a distant car seat
- I could go and watch sports events (a lot of wheelchair users become active sports users)
- I could go shopping and even take a look around instead of just getting what I needed from where I knew it was
- I didn't need to be pushed
- My kids and their friends thought of it as 'pretty cool'!!

Well that was over ten years ago. If there's one piece of kit that has done more for my life than any other – it's my wheelchair. To summarise – Life would be much better without HSP, but I can't change that, however, with my wheelchair I can do far far more than I could otherwise do.

As well as Wheelchairs themselves, there's a whole range of 'add-ons' like Hand cycles (great for a bit of aerobic exercise), and Powered Trike adaptations –

IT'S NOT THE TERRIBLE THING THAT YOU MAYBE FEAR.

Andy Barrett Region 4

Members' Letters

Hello! Let me start by introducing myself, my name is Peter Bateman and I live with my wife Sandra in Porthcawl, a seaside resort on the South Wales coast. Sandra was diagnosed with HSP in June 2004 from the results of a DNA test and has had problems walking for some 15 years; it is difficult to say when the condition first started because it has developed gradually over time.

We did a lot of internet searching to try and learn more about the condition and in the process found the HSP self help group and joined. As there are no meetings in our area Ian Bennett encouraged us to attend the West Country meeting held in October 2008. We had mixed feelings from family and friends about attending because some thought we may be upset to see others with the same condition, but this could not be

further from the truth and is the reason I am writing this.

We did attend the meeting which was held at the Dartmoor Lodge in Ashburton Newton Abbot on the Saturday. We were first to arrive at 1100 the meeting was not due to start until the afternoon but we wanted to be there in plenty of time. Other members started to arrive and we sat around a large table set out by the hotel staff for us all to have lunch, it was obvious from the greetings that they all seemed to know each other very well but we did not feel like outsiders as we were given a very warm welcome by all.

After a good lunch we moved on to a smaller room for the meeting which was very relaxed and informal, Ian kicked the meeting off by welcoming the people from Wales (I think that was us). He then introduced Dr Jane Grose from Plymouth university who explained that she was carrying out a study of HSP awareness within the health service in the west country. An open discussion followed regarding the type of information required and how many people were interested in taking part in the focus group meetings that she would be holding at a future date.

Open discussions followed in a very relaxed style about all manner of issues that members wanted to raise to the group as a whole, members mingled about the room entering into smaller discussions with each other. Let me convey to you that at no time were we put on the spot or felt uncomfortable in any way during the meeting.

As the meeting proceeded we had a raffle to help raise funds, some members won several times and kept putting the prize back for re-draw we all thought it would go on forever but eventually all the prizes went. As the meeting drew to a close some members who lived near went home and the rest of us stayed for the evening meal.

The evening meal was again around the big table that we used for lunch and there was plenty of conversation flowing. I sampled the "Steak and Jail pie" yes it is jail not "Steak and Ale" due to the Jail Ale they sell at the bar, must be because of the prison

that's not too far away, they also sell Firefly but that's another story. After a good meal we adjourned to the bar area to relax and enjoy the atmosphere around the log fire which was housed in an unusual iron hanging basket very cosy indeed. All good things come to an end and it was soon time for bed we had to be up early for breakfast the next morning for the trip home.

We are very glad that we attended the meeting and found many new friends, Sandra at no time felt upset to see others with the same condition as her in fact it has given her an inner strength knowing that she is not alone with so many people ready to help and support each other but at the same time would not wish this condition on anyone. If you have been unsure about attending a meeting then give it a go, I know you won't be disappointed.

Peter Bateman Region 6

Dear all

On the 30th September, Ian Bennett and I travelled to Buckingham Gate, London to receive a cheque for £3,200 kindly donated to our Support Group. We were greeted by Jane and Simon who made us very welcome and took us upstairs for a drinks reception.

Each year employees from Rolls Royce do a sponsored run, and everyone who runs can choose a charity they would like the money to be donated to. They each put selected charities into a hat and two were drawn, and last year we were selected with Ovarian Cancer Action to receive its support. We asked who had put our charity forward for this award and was introduced to Gemma. We had a lovely chat with her, she told us that she has three cousins who suffer with HSP and they are members of our group.

We were then presented with the cheque and had a couple of photos taken. We spent some time chatting to some of Rolls Royce staff who completed the run, and to celebrate a wonderful day, we were invited to stay for an absolutely gorgeous three course lunch and red wine. To top it all we were waited on by a butler, who attentively served our every need. It was such a lovely treat!

Just would like to say a big thank you to everyone at Rolls Royce for a very memorable day.

Lorraine Saupe Region 1

Here I am once again, this time giving my account of the the North West meeting on Sunday 19th October in Blackburn.

It all started at 10.30am with teas and coffees (a little late getting these to us but they made it in the end). John Morris introduced himself. For John there were quite a lot of nerves before with all the preparation but this turned out be a good meeting, although he couldn't wait until 4.30pm when everything had been done and he could relax.

It was an excellent turn out (32 people) with regular familiar faces but it was good to see new ones, possibly people new to the group or ones that just haven't been to other meetings.

Thanks go out to Carol McFadden and Wendy Watson who gave up some of their precious time to be with us to speak about and demonstrate the Functional Electronic Stimulator (FES). There were two or three people in the room who already use this and we had a demonstration from Ian Bennett (Group Membership Secretary) who together with Dave and Carolyn Harris, had travelled some 400 miles from Dorset to be with us.

Carol and Wendy gave people a chance to try this to see if it would be suitable for them and speaking with several people afterwards this seemed to be something that they could look at to make their walking easier.

We then went on to have lunch, a selection of hot and cold food to suit most tastes but sadly for a few of us there wasn't a dessert, this came later in the afternoon with tea at approximately 3.00pm.

John got up and read out the script he had prepared. This was excellent, funny in places but true and if you were there you will have some idea of what I mean.

People then had chance to mix and mingle which I think always works. It is wonderful to have speakers but "we" as you all know

are the "professionals", we are the ones with it.

It was now 4.30pm and John could breathe a sigh of relief. Before leaving I spoke with him and reassured him that it had been good and he agreed so hopefully there will be more Northern Meetings, probably not in such a luxurious place as the "Directors Suite" at Blackburn Rovers Football Ground because it doesn't matter really where such a good group of people can meet.

I know the group is split into regions but they don't really mean anything if a group of people can get together for a chat.

I would again like many more of you to thank John for all his efforts. And I personally would like to thank Mark Tomlinson for once again being my chauffer for the day because without him I would not have been there.

Debbie Best (Region 10)

The Wheelchair

In October 2008 Sandra and I decided to take a holiday near the Kennet and Avon canal at Bradford upon Avon. We like the idea of a canal holiday but think it may be a bit difficult with Sandra being in a wheelchair. We spent a lot of time at the deep lock in Bradford watching and helping the boaters as they negotiated the lock. There is something therapeutic about messing about with boats. Sandra was able to sit in her wheelchair and watch all the action as the boats went through. There was also time to chat with the crews and we met some interesting people along the way, one chap had come all the way from Australia!

We decided to look for some more action and found it at the Caen Hill locks. Situated on Caen Hill, this flight consists of no fewer than 16 locks. The Caen Hill Locks are part of a longer 29-lock flight at Devizes, all packed into just over two miles. Well we had plenty to entertain us here and they even have a very nice cafe at the centre of the flight for refreshments, anyway back to the reason for my story.

After all this activity we decided to take a trip on an organised tour boat passing through the lock that we had helped so many others to negotiate at Bradford on Avon so booked a trip for 1430 the following day. We arrived at 1400 a bit early but we always try to arrive at destinations early these days to allow for any holdups or trips to the loo. You can even get a puncture in the wheelchair you know! Two men were working on the boat and said give us about 15 minutes and we shall be ready for you, so we had a cuppa at the cafe which was next to where the boat was moored and we could see what was going on. At this the boat moved away from the bank heading very slowly for the other side it then started to reverse and turn around, this was a 60 ft boat turning in a canal about 80ft wide at this point so it took some time just like a three point turn but with eight points.

This was all very interesting to watch but did puzzle us somewhat because the trip was in the other direction! Now it was going to have to turn around again to start the trip A man standing next to us who had come off his own boat was also watching this spectacle, so thinking he must know the ways of boating more than we did I asked him why the boat was turning around when we are going to be setting off in the opposite direction on the trip. He looked at Sandra sitting there and said in a dry tone apparently someone in a wheelchair has to get on board and the wheelchair lift is on the other side of the boat! Well it was so funny we all had a good laugh, so wheelchairs aren't always bad news.

Peter Bateman Region 6

Della's story

At the beginning of 1998 I was married with 3 children. I had not had any real signs of H.S.P. Well, I didn't know anything about it. There were no other family members with it or who had heard of it. I used to trip occasionally, but that was all.

By the end of 1998 my marriage was over. We had been married for 15 years. I won't go into details. But obviously it wasn't

working. Anyway, in 1999, I got together with my husband, Roger.

In 2000, I started getting problems with walking. Cramps in calf muscles when walking and slight foot drop. I just put it down to me not picking my feet up properly.

Anyway, in summer 2002, Roger and I got engaged. In May 2003, I went into Royal Free for tests and was diagnosed with H.S.P! I was told that I wouldn't get better and that all they could do was control the symptoms. I went into a deep depression! I would go to bed all day, just to get up to do a few house jobs. I felt worthless and told Roger to leave me, because, I didn't want him having to put up with me, having to rely on him. He didn't deserve it, because he is a lovely man, with a heart of gold.

Who would want me! I am disabled! But Roger refused to leave me. He saw me, not my affliction, and I now know that I am loved for who I am, not for H.S.P. Believe me, I went through a hell of a time. I would cry all the time, would be angry, a complete mess. I really believed that nobody would want me. Roger never let me down and was supportive every time I had a low.

I still have down days and am very lucky that I have a soul mate as a partner. But I do believe without a doubt, in fate. There is someone for everybody. And if it's meant to be, it will be. If someone can't see you as a person, but only as person with a disability, then they are not right for you.

Della Brookman Region 3

The following letter was received on the group's email facility when members were discussing their hobbies:

.....doesn't cost me any money, requires no physical effort, can be done at any time - I can spend 5 mins or as long as I want and it is so rewarding in financial terms. How many hobbies leave you in pocket?

I enter competitions!

I started when I gave up work to have a family nearly 30 years ago, before I was immobile, to help the family resources.

Winning the children mountain bikes, swing, slide, etc helped the family finances. Competitions were the slogan/tiebreaker type back then but now require little brain power and are usually free prize draws.

I don't mean to brag but I've been on Concorde, the Orient Express, in a hot air balloon, won foreign holidays and UK weekend breaks as well as TVs, washing machines, ipods, mobile phones, digital cameras, supermarket shopping vouchers, etc. and all for very little cost.

This year we had a week in St Lucia, £3000 cash, £500+ worth of DVDs and CDs, subscription to Sky Plus free for a year, plus numerous other prizes.

I do not enter any phone or text comps because of the expense but know people who do and who have won lovely prizes. In football terms I would not put myself higher than Division 2 with respect to winning and know loads of people far more successful than me. I belong to a number of closed email groups of like minded people where we share everything and help with tricky answers.

I enter comps mainly online or by email. I do some postcard entries so have to pay for postage but get all my postcards free - just look on the beauty counters of dept stores, fashion shops, leisure centres/gyms, libraries, student bars and cinemas.

If anyone is interested I always say look in your local paper and listen to local radio. The prizes are small but so are the number of entries. Over the years I've won tickets to local firework displays, local tourist attractions, county show, craft shows, local shows and events. This time of year there could be tickets to a local pantomime, craft show, shopping vouchers and more so always worth having a go.

There are lots of comps to win "money can't buy" prizes such as tickets to red carpet film premieres with after party hospitality where you meet the stars. There are similar prizes involving various sports or pop groups - whatever takes your fancy. Doesn't interest me but I know people who love winning this type of prize and they have won trips to

cricket and golf tournaments, the World Cup and even the Olympics.

Take a look here

<http://www.loquax.co.uk/>

to see what's on offer. I think you may have to be an active member to view the postcard and email sections but I think you maybe surprised at just how many web based comps there are.

A word of warning - it's best to use a "spare" email address just for comps as you'll be bombarded with spam and you wouldn't want your personal and family emails to get lost amongst it all. A lot of people give up after a short time - it takes dedication and perseverance but anyone can do it, just give it time. Today I received a wem (winning email) telling me I've won £100 craft/card making goodies. I have no idea exactly what the prize includes so it will be a lovely surprise when it arrives. The "feel-good" factor is enormous as I never know what the postman might bring me, get a phone call or email any day of the week. I have "won" numerous time share holidays and discount vouchers which I discard as "non-prizes". If you have to spend money to get a prize then it isn't a prize but an offer and usually available through the normal channels.

I have won prizes I don't want - usually because I wanted the main prize and ended up with a runner up prize. If family or friends can't use it I give it to a local fund raising event for a raffle prize or sell it on ebay.

Now next time you're browsing online, flicking through a magazine or newspaper or in the supermarket and see the magic word WIN you'll look at it twice. Oh yes, instant wins are a waste of time and money and I only buy if the item is on my shopping list. I know someone has to win but the odds are stacked against you. Once a soup company printed 6 million promotional labels and there were just 100 prizes on offer. Think how much soup you'd have to buy to win!

Any questions?

Ursula Bingham Region 1

Regional News

Region 4

On the weekend of 17th & 18th of Jan 2009 the University of Plymouth held a series of focus groups with members of the HSP Group region 4, this was part of the study by the university to see how healthcare services are received by HSP affected people in the South West. The meetings were held over two days at The Dartmoor Lodge Hotel, Dr Jane Grose from the university conducted affairs, on Saturday two meetings were held - one in the morning and then one after lunch, these were for HSP affected people only, on Sunday Dr Grose held meetings with some of our carers.

About twenty Group members attended over the weekend including new members - Marion Matthews and her daughters - Louise and Rachael Davis. Having never attended a focus group before I wasn't sure what to expect so I was pleasantly surprised to find it all so easy-going with lots of humour. We gave Dr Grose lots of assorted information for her research, she is also getting input from our GP's, Neurologists and Physiotherapists. Using this research the University of Plymouth are hoping to be able to make recommendations to our healthcare groups on how services can be improved.

David Britton Region 4

Regions 1 and 2

Meeting November 15th 2008.

The process of deciding and booking speakers for the Milford Afternoon Teas covers many stages.

Choosing a Speaker who is both interesting and relevant is, of course, most pertinent, but not always easy.

Many HSP sufferers have, previous to their diagnosis, been involved in sports and sporting activities. For many, the lack of being part of a team and the routine around the sport is badly missed. With the limitations of our lower body finding a sporting exercise is difficult. We need to stretch our lower

limbs, but also ensure our upper bodies can take the extra demands we may put on them. For many, bowls fits the bill, but is not for all.

A couple of years ago a lady from 'Extend' joined us. As some of you may already be aware that Extend is a way of exercising to music from your seat, be it a chair, stool or wheelchair. During the demonstration we were provided with scarves which added to the fun.

At the beginning of 2008 I had the opportunity to go to Pilates and enjoy the exercise. Of course there are some I struggle with, but there are a considerable number that benefit both my upper and lower body. For those that use self propelling wheelchairs there are benefits to stretching out shoulders and arms which are much used.

Our speaker last November, Gill Keitch, teaches Pilates and has experience in teaching Chair Pilates. Exercises like Yoga and Pilates, are often recommended to us, but for many getting up and down from the floor is not always possible. We may have to do it following a fall, but as part of an exercise regime is not an attraction.

Some of the exercises that Gill demonstrated highlighted the combination of breathing and core muscle control whilst exercising the upper body. There was also the option of using bands to lift and stretch arms and legs. We were fortunate that Gill had an understanding of the limitations of HSP and, consequently, demonstrated suitable exercises.

There are a number of books available about Pilates, but there is also a DVD specifically for Chair Pilates produced by Stott Pilates.

With best wishes,

Jane

Region 9

Blackburn HSP meeting

After several months of planning a meeting took place in the North West at Ewood Park Blackburn (home football ground of Blackburn Rovers) on Sunday 19th October.

My involvement began following difficulties the region 9 coordinator Mike Cain was having finding a suitable venue. I made a total of 43 requests to hotels, councils, hospitals, halls, schools, colleges, universities etc which resulted in only 6 replies of which 5 turned out to be unsuitable with reasons like, too small, could not cope with disabled people, not available at weekends. So with only one possibility I was left with Ewood Park at a full price cost of £39.50 per person or around £1800 in total! Numerous discussions followed and Blackburn Rovers became more and more interested in helping us by sponsoring our meeting. This did not quite mean the meeting was free but the overall cost dropped to around a quarter of the full price. Having secured approval from Mike Cain and Ian Bennett to make a firm booking I offered to continue with the organisation not being aware at that time I would end up organising the whole meeting. It was not an easy few months and many problems arose taking a considerable time and effort to overcome.

As the clock ticked away on Sunday 19th a big relief was felt as the day progressed and by mid afternoon my nerves were more relaxed and I was beginning to realise it was a good day which those present were enjoying and I could start doing so myself. 36 HSP members and friends had booked to attend and on entering the stadium we were immediately aware of 5 star treatment in a luxury venue. Unfortunately 5 members were unable to attend on the day. A lift took us up to the third floor where we emerged into a room described by my wife as looking like it was ready for a wedding reception. There was a huge window with a view of the pitch from the Blackburn end of the ground. Harry our main steward for the day and his staff had welcomed us and we began making slight adjustments to the layout and doing those important things like setting up the raffle.

Coffee and biscuits were available from 10.30 and Ian Bennett and I gave a brief introduction to the day before Carol McFadden began her talk on Functional Electrical Stimulation. After seeing me in

front of the group armed with pages of notes it was amazing to see Carol informing us without reference to notes. She was joined by Wendy Watson and members freely asked questions and made contributions as we were treated to a most excellent presentation. I had thought some of the day might be spent watching a match in progress but even if there had been one, we were captivated for around two hours by the information we were given.

Carol and Wendy had explained their work and the background to how FES was developed, how it works and the benefits from its use; the conditions it is suitable for as well as those for which it is unsuitable. They explained the criteria a person is required to fulfil and the precautions of usage together with how it is funded and the costs involved. They ended with a demonstration and information from members already using FES and a practical session for those who wished to try. FES is available in the North West and more detailed information is available on www.neurocarephysio.co.uk or by contacting FES North West Ltd, 5 Main Street, Warton. LA5 0NR telephone: 07920864990

Lunch was from 1 till 2, being a good buffet of hot and cold food. The meeting continued with a video showing the work of the HSP group in the south west area which included many familiar faces. We wondered why Ian Bennett was so keen for us to see it! Meanwhile Carol was continuing to allow people to try out FES to see if they were suitable for its use. Then I, nervously, faced the group to explain my involvement in HSP, my work organising the meeting and to discuss possible future meetings. I soon realised what a super group of people I was talking to.

The meeting had been organised on similar lines to that of an AGM, like the two previous North West meetings in that we had a good venue, speakers and of course good food not forgetting a raffle. Such organisation and style comes at a considerable cost both in the time and effort taken to arrange but also financially. By charging a contribution to those attending and getting such generous

sponsorship from Blackburn Rovers we still required a sizable contribution from HSP funds. Basically it was decided that for future meetings they would need to be more self funding and perhaps more informal arrangements which work well in other regions, leaving major speakers for the AGM.

Before afternoon tea and cakes we drew the raffle and I was concerned over what to do afterwards so several DVD's and videos were ready if needed. Members began free discussion and mingled with each other and the remainder of the day passed with a gradual departure starting around 4pm. with the meeting finally ending about half an hour later.

There are many people who need to be thanked for the meeting but particularly Blackburn Rovers FC and Yvonne Watson of Northcote at the Rovers who was the main contact for the organisation along with Harry and his team who looked after us so well on the day. Ian Bennett, Dave and Carolyn Harris for travelling up and bringing the necessary technological equipment. Their support was greatly appreciated. Carol McFadden and Wendy Watson our FES speakers. Not forgetting my wife Katherine, daughter Zoe and son in law Paul for all their help over the past few months and on the day too and of course to everyone who attended. It was so pleasing to see so many people there enjoying the day and being able to meet up and talk informally with each other.

If anyone can suggest a suitable venue for a future meeting please get in touch and even better still if anyone 'up north' could help to arrange a meeting I am sure we would very much like to hear from you - it does not have to cover the whole of the area and be on the scale of Blackburn!! Just a place where a group could meet informally for a few hours would be ideal and additional things like parking and disabled access need to be considered as do some refreshments. It does help if it is convenient for members to get to - near public transport and easy to find by road. Oh and do not forget a raffle too! If you do know of anywhere which might be

suitable please contact Mike Cain, Ian Bennett or myself (01539 821870)

John Morris Region 9

Forthcoming Events:

Region 4 get together

Saturday April 11th 2pm onwards
The Dartmoor Lodge Hotel – Ashburton
All members welcome. For further details contact Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday April 18th 3 – 6 pm
Milford Day centre
Anyone interested in attending, please contact Jane Bennett on 020 8853 4089

Naidex

UK's largest event for homecare disability and rehabilitation
28th – 30th April 2009
NEC Birmingham
<http://www.naidex.co.uk/>

Mobility Roadshow

4th, 5th & 6th June 2009
Kemble Airfield near Cirencester,
Gloucestershire
Open daily 10am free admission and parking
www.mobilityroadshow.co.uk

HSP Flying day

Friday August 7th
Lasham Airfield Hampshire
½ hour local flight at the controls of a light aircraft and lunch.
£50 per head (only six places available)
Call Ian Bennett on 01202 849391 to reserve place, but don't delay as places will go quickly.

HSP AGM

Saturday 20th June 2009
10-15 am – 4-30 pm
Trident Technology and Business Centre at
Royal Leamington Spa

New Members

We welcome the following new members:

Mrs Angela Barnicoat Mid Glamorgan Region 6	Isabel Pearson Fife Region 11	David Crossey London Region 2	Sylvia Garrad Thame Region 3
Barbara Grant Merseyside Region 9	Justine Begg Bolton Region 9	Frazer Lindsay Edinburgh Region 11	

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

Useful Contacts

	<u>Email</u>	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
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
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne , Dorset BH21 2DQ	ian.bennett@tesco.net	01202 849391
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
John Moore – New Member Co-ordinator	john@moore108.orangehome.co.uk	02392 592784
Peter Bateman – Region 6 co-ordinator	pete@peterbateman.co.uk	01656 788502
Michael Cain - Region 9 co-ordinator	Mikeregion9@fsmail.net	0161 456 7531
Liz Ferguson - Region 11 co-ordinator	lizferguson1@ntlworld.com	01415 779695
Colm Treacy Neurogenetics Clinical Nurse Specialist	colm.treacy@uclh.org	020 76762115

AGM & Conference 2009 Saturday 20th June

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

- 10.15 Coffee & Welcome.
- 11.00 AGM
- 11.30 A short break
A speaker will be found for this slot, but the intention this year is for more social time
- 1.25 Lunch and the chance to mingle.
- 2.40 Dr Christos Proukakis The Royal Free Hospital:
An overview of HSP highlighting some of the genes.
- 3.40 Coffee and open Forum: Simply relax and talk over the day amongst friends, old and new.
- 4.30 Close

The above is an early attempt at an agenda for our AGM to give an idea of the day's proceedings. We are intending on having two speakers, enabling us to have more time to talk to one another.
