



HSP Newslink

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

Issue 18 – September 2009

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

No longer feeling alone



Eileen and Kathleen McCarrick at our AGM in Leamington Spa on June 20th

My name is Eileen McCarrick and I have suffered with H.S.P. from birth. I have been a Newslink receiver for a number of years.

For years I've read about the meetings and region get together, but this year our Region 6 co-ordinator Peter Bateman contacted me and I and my daughter Kathleen who also has H.S.P went to Porthcawl.

Oh was I nervous, fearful, of meeting someone who had the same condition as myself and my daughter. I grew up in south coast Ireland out in the country in the valley of Slieve Nāmbōn.

As a child I was told that when my mother carried me in her tummy her pregnancy should not have gone full term, it should of

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aborted but God wanted me so I was one of life's miracles. I was happy with this because what was wrong with my legs never had a name. I had the thoughts in my head that if I worked at the things hard enough I could walk like everyone else. It was hard being so different as a child, name calling and going to school in a convent, the nuns made me walk from class to class with a glass of water on my head, but I kept smiling.

I grew up on a farm with a large family and at the back of the farm was a meadow. It had a complete hedge of wild honeysuckle or woodbine, as we knew it and on a sunny day this sent out a soft, wild heady perfume that mingled with the smell of the new mown hay. You had to stand still with no shoes or socks on and close your eyes to fully absorb this feast of fragrances.

When daddy resumed cutting I usually stayed on and I would run around the field bare foot mostly falling over and exploring mossy ditches and picking wild flowers until finally the last swarf of hay fell. There was a stream and you could spray the water over your feet and splash the warm feeling of being a child and in my head I would plan being able to run around that meadow without falling all the time and be able to pike the hay with the fork without losing my balance, and because I was a miracle this was possible.

Now I was going to meet people with the same condition as me. Was this the end of hope? Would my memory, my long life plan, my dream come to an end?

Oh it was so different I met so many people and that fear was gone. While at the region 6 get together in Porthcawl I did tell Peter I would go to the A.G.M in Leamington Spa.

When I got home from Porthcawl it was difficult for a few days, I was trying to stay positive, my daughter Kathleen was talking to Emma on the internet and Kathleen was getting excited about meeting another teenager with the condition and for this reason I said I would go.

It was an eye opener I met Christine, Laura, Mark, Lorraine, Emma and Ian, all around the same age, I was no longer alone, ok I was not a miracle but I was not a freak of nature which is how I had been treated as a kid by

other kids. I laughed, I smiled, all my wall which I had built went down. We spent hours laughing with each other in the Green Man pub. Kathleen and Emma had a good laugh with Peter and Kathleen came out of her shell. It was a wonderful experience and she is now talking about having fun with Emma and Peter in Devon.

This time when I came back from Leamington Spa my feelings were warm and maybe it was watching how happy my daughter Kathleen was. The confidence she was showing was heart warming. When I was growing up in Ireland as a child all five children were reared as free as birds. We were free to be children and grow up with fun, to grow up at a quiet pace and now I could see this quiet confidence in Kathleen. She was not alone as a teenager with this condition. She has met Emma and together they would and could grow stronger, thank you to all at Leamington Spa A.G.M

Eileen McCarrick

Chairs column

Having been elected as your chairman at the recent AGM it is time to introduce myself! I was born in Manchester and am the middle child in a family of five. My life has been spent working with technology in various industries.

I have worked on the railway, for a computer manufacturer, a software house, Reuters news agency and for telecommunications companies. I now work in London at a Bank looking after some of their computer security equipment. It is a job that consumes many long hours over two shifts with call-out.

My hobbies and interests have included the following many of which I have had little time to pursue recently! Electronics, Amateur Radio, Computers, Alternative Technology, Industrial History, Conservation, Singing, Flying, cycling, Real Ale and Personal Development. Some of these are very old interests though when I stop working full time, I will be able to revisit many more of them and have much more fun!

As your chair, I intend to help coordinate the activities of the committee and I have a special interest in liason with other European HSP groups.

My HSP appeared in my late forties when inexplicably I would find myself tripping up and giving myself black-eyes. On the third occurrence I agreed to see my doctor. Being referred to a Neurologist, I was prescribed an increasing extended diet of Levadopa. This was to remove Dopamine Responsive Dystonia as the possible complaint. I was confirmed to have HSP after taking up a digestive reaction to Levadopa.

Unfortunately as is predictable, my muscles are stiffening more and I cycle much more slowly now. It was a great joy to have been able to cycle the length of Great Britain in 2005 for this organisation and I am not so sure I'd be able to do it again unless it was very slowly. Many thanks for all the support I received from many members then. I look forward to encouraging any members who would like to cycle back onto their bicycles. I am looking into using electric bicycles now as climbing hills is less achievable. I also find certain pedals that help my feet placement. I hope both these are interesting subjects for future articles.

I look forward to meeting members at meetings and the AGM.

Richard Williams

Secretary's Spot

Now we're at the end of the summer period and having to think again about autumn and winter, it is perhaps a good time to reflect on what an organisation like ours does for people.

It is clear that many people with HSP get a great lift from meeting and talking to others. Just the fact that "I'm not alone" seems to be important. From being in the organisation over some ten years now I have drawn some other conclusions about people with HSP. I'm sharing these because I strongly believe that anyone who recognises any of these effects within themselves can take action to improve the way in which they can cope.

Obviously after the "not alone" effect has worn off there is more to be gained from talking with a range of members – some will have learned to cope and work through the situation that you are now in. They will be able to share what they did and what they might have done better. In this area there are several members who have said they wished they had taken up the "next level" of aid earlier. Moving from one stick to two, changing from sticks to a walker, changing to a power chair, using a wheelchair as part of a normal day, getting an FES assessment – all these have been mentioned in these pages and at our meetings. As it is such a common theme I commend every member to think hard as to whether they are "at the right place" with what they are using, or whether there might be something they could use now to get more from life.

This brings me neatly back to the time of year, because this space before the nights draw too far in is a good one to do your research, to go to a meeting to talk and learn or to visit a Disability Living Showroom or a shop to try out a possible new bit of equipment. Most people who have made the effort seem to have gained from it!

See you at a future meeting?

Dave

A change is needed for mothers like me

Having a baby should be one of the happiest times in a mum's life. Sadly, mine wasn't.

I have a disability called Hereditary Spastic Paraplegia which, in my case, means I use a walking aid.

That aside, I try to live life to the best of my ability.

In November 2007 I gave birth to a beautiful girl.

Before the birth I had done lots of research, finding out the impact of childbirth on my body, how I would adapt to take care of the child, etc, etc.

The hospital midwife devised a plan for when I was in hospital. It involved the midwife visiting my home to see what adjustments could be made, to show me how to wash and care for the baby. It also included providing an adjustable cot and a low bed for when I was in hospital.

I had wanted a natural birth, but as things turned out I had to have a Caesarean, which meant I would face a long recovery period.

To my surprise the disability midwife was not present at the birth, and when I came to I found that no special arrangements had been made for either myself or my baby.

I also had a terrible reaction to the drugs that I have been given.

When I returned home my boyfriend was there to help me. However, his two weeks' paternity leave soon came to an end.

My health visitor suggested that the social workers would help, but to my horror, a few days later I received a call from the child protection people who told me that I was a liability to my baby. There were concerns that I could drop the baby.

I was told that my boyfriend should become a full-time carer for myself and the child.

I was distraught. My boyfriend was given time off work but we remained fearful that our baby would be taken from us.

I made many suggestions, but I only received negativity. My request for a home help was refused on the grounds that the adult homehelp service could only help me and not the baby.

The social worker advised me to apply for a nursery place for the baby, but for whatever reason the forms keep getting mislaid.

I have also had a visit from Scope, the national charity. They hold many classes for mothers and babies which would benefit us. I successfully applied for a "Cumfy Bus" pass but was told the baby could not remain in the pram but needed a car seat.

This means I would have my walking aid in one hand, a pram in the other. Where would I balance the car seat?

We are told being a parent is such a positive experience.

Not mine. For me it has all been so deeply frustrating....

Why does there seem to be so much help for parents with disabled children, and yet nothing for disabled parents? And why aren't there any groups for people like myself? Maybe it is time we started one.

Donna Scraggs Region 9

Lasham day out

By Peter Bateman

On Friday 7th August The BDFA (British Disabled Flying Association) held a flying day at Lasham airfield in Hampshire. This was for people with HSP to experience the pleasure and freedom of flying a light aircraft.

Sandra and I went along arriving at 10:00 on the Friday morning, this was our first visit to a BDFA meeting and also our first visit to Lasham.

Sandra was not going to fly because she tried it once and it made her arms ache (all that flapping!) but we wanted to attend and join in the fun, meeting friends and new members of the HSP group.

Lasham is the largest gliding centre in the country and is quite an impressive, well kept airfield. The main building has a very respectable restaurant serving a nice range of food and drink throughout the day. In front of this building was a large marquee with tables and chairs leading on to the main spectator area with bench tables set out in beer garden fashion on the lawn. The day started with a briefing for those taking part of the basic controls of an aircraft, this was demonstrated by Shona Bowman, the flying instructor using a wooden model which had about as much chance of flying as a house brick!

None the less it did get the point across and if any of the intrepid pilots had any qualms about flying with a young female pilot these were soon put to rest when she announced that her day job was flying an airbus for BMI no less!

The flying got under way and ran like clockwork thanks to the tireless efforts put in by Ian Bennett and the team. The weather was kind to us and all who wanted to fly did so and enjoyed the experience. Most of the flights took place with Shona as instructor pilot. Shona's husband Paul took two flights as pilot, he flies for Virgin, I wonder what they all talk about around the breakfast table.

Alan Meredith took Stephanie Flower for a flight and she was also in very capable hands as Alan is the chief pilot of the British Antarctic exploration team. All these people volunteer their time to help the BDFA, what a wonderful bunch.



Stephanie and Alan Meredith at the controls

While this was taking place there was a great deal of glider activity to watch from K13, wood built gliders to high performance glass jobs, some being towed up by winch and others using aero tow.

Towards the end of the day some of the sleek glass fibre ships flew low and fast over the spectator area and dumped their water ballast over us only to shoot back up in the air and climb away a lot lighter gaining a few more minutes flying time before finally landing. This was not an unpleasant experience as the water came down in a fine mist and felt quite refreshing, yes it was quite warm that day believe it or not.

In the afternoon while all this activity was going on a Boeing 737 passenger jet landed going to the far corner of the field to be serviced by the Aviation Tool Company who have a facility at the airport.

The non flyers had a great time watching the proceedings and enjoying the wonderful social atmosphere.

This was a most enjoyable day out and we look forward to the next time we can visit Lasham airfield.

The BDFA are a wonderful organisation giving disabled people the opportunity to fly and also go on to obtain a private pilots licence through a possible scholarship.

For further information on the BDFA, please visit: www.bdfa.net

Useful Information

Travelling with HSP

Of course we listened to the advice about pre-planning and, when we needed it, that is what we would do, but a train ride to the Cologne Xmas Market, that should be a doddle!

Our very kind brother gave us a lift from his home in North London to Waterloo Station with plenty of time to take a slow walk to catch the Eurostar train.

First mistake was attempting an escalator with cases. The instability of HSP doesn't allow for travelling on an escalator with a case. We walked on to the bottom step of the upwardly mobile escalator with Terry ahead of me for me to help. No problem! and I stepped onto the escalator behind him. Then things went awry. He full backwards on to me and we both finished up with legs in the air and cases doing their own thing back to the bottom. I quickly realised that I had a short time to get out from under Terry, get myself upright and then help him before we reached the top and I shall be eternally grateful to a very kind stranger who helped me to get Terry back on his feet. We reached the top with minor injuries thankfully. However, the cases were at the bottom with no means of getting back to them easily. I daren't think what I looked like as I scampered back down the upwardly mobile steps to retrieve them. Later I could see the funny side of all this and my imagination went on to cartoon tilt as I recalled characters I had seen flattening and dividing into strips as they were dragged into the top

of the escalator only to reappear and jump back up whole at the bottom. Glad we didn't have to try it out!

We learnt our lesson and our next 'expedition' - Oh OK! it was only a flight to Nice - we agreed to pre-plan. Our phone call established that we could get a wheelchair at check-in to take Terry to the boarding area. Great! Off we went. What we didn't take into account was how we got from the car to the check-in. Fortunately, I found a wheelchair that had been left at the entrance doors. All we had to do was get a wheelchair and a trolley of cases to the check-in.

Whoops! Only one pair of hands to push two things. Toot-toot, here comes the train as I pushed Terry in the wheelchair and he pushed the trolley of cases. Braking was a little precarious, but it solved the problem.

Needless to say, this was the start of many more escapades. We have learnt that losing luggage can be a major problem when you are on a small island and one of you can only walk a short distance to replace necessary items. We have learnt since that luggage can be sent separately (although we have yet to try this). Wheelchairs are very limited on cobblestones! Rite cars become a nightmare when you arrive at a major airport overseas and have to get from one side of the airport to another. The previously mentioned train system only works well on flat surfaces, so getting in and out of lifts and transferring disabled husband, wheelchair and cases on and off buses needs a very healthy partner - how do people on their own manage? We haven't learnt all the answers, but we overcome one problem at a time and the next time becomes a little easier. We don't really have a choice, we are not the type to sit at home and do nothing.

I'm sure there are many of you with your own stories of difficulties faced, but for those who are just beginning the HSP journey, I thought it may be good to hear that problems are only there to be solved and although difficult at the time, they are things that allow us to share laughter later.

Patricia Reed

Members' Letters

Hi Stephanie,

Hope you're well and the new dog is continuing to train well and Frodo is being looked after as he deserves in his well earned retirement!.

We recently tried to get repairs / spares for a mobility scooter and got nothing but rebuffs from many mobility specialists including the manufacturer. We eventually came across a brilliant owner managed company based in Addington, Croydon who was able to undertake any repairs / servicing on any makes and even if necessary make/modify other parts if machine obsolete, etc. A brilliant, personal and extremely reasonably priced service and one that might be of interest to others in the area between say South London down as far as the South Coast :

Barrie Semark
Barrie's Mobility Service
91 Homestead Way
New Addington
Croydon
Surrey
CRO OAW

Tel no: 01689 845942

Mobile: 07779 096888

His card says that he also deals with and sells Rise & Recline Chairs, Electric Beds Stairlifts, Walkers, Rollators "and other products for the less able" You might like to keep this on file, perhaps if you could circulate to our members / area co-ordinators in the relevant areas ?

Best wishes

Gill Ransom Region 1

Dear all

After chatting to Ian Bennett on facebook for a while and him encouraging me to go to the A.G.M, we decided to go to the June 20th conference.

We also, decided to stay over night at a hotel, so that we could socialise with others that attended the function.

Apart from getting lost, we just managed to arrive just before 11 A.M. We managed to say "hello" to some people, before Lorraine beckoned to us from the table right in front of the committee.

We enjoyed both the talks given, even though the poor Neurologist got lost too. He gave a very informative short speech. I found that very interesting, but would have been nice to hear it in full. Can't be helped. These things happen.

We had plenty of breaks with refreshment. We also managed to talk to some others that were there. We found everyone helpful and friendly and we are definitely glad we went.

The evening was very pleasant too. It was good for me to chat to and listen to other's experiences with H.S.P.

We will definitely be attending next years A.G.M. :-)

Della Brookman.

Hi everyone in H.S.P land.

I just want to share with you the Experience of Airport Wheelchair access at Luton Airport this summer.

I decided to try out the Wheelchair access when my Husband, Daughter and Daughter's friend and I went on holiday at the beginning of August 2009. We had been earlier, in July to one of the Canary islands. On the way to the Canaries, I struggled with all the walking and the long plane journey. I nearly collapsed with exhaustion, when we had to walk half a mile to the coaches, because they were having building work done at the Airport. Also, when we returned a week later, I nearly collapsed again and had to stop, because my legs just gave up. I managed to get to the car, but found the whole travelling experience exhausting.

Anyway, I looked up Airport Wheelchair Access on the internet. Found out that all I had to do was phone my flight provider, give them our holiday booking reference and they arranged wheelchair access at both airports.

We arrived at the airport. You can use the Disabled access phone in the car park to arrange for a wheelchair to be brought to

you. I walked into the departure of Luton Airport myself, using my two walking sticks. Went and booked in our cases and made ourselves known at the check-in desk. They give you your plane ticket with a code on it. Then you take it to the Special needs counter, where all the wheelchairs and helpers are. They take your ticket then you have a wheelchair assigned to you. It's all taken care of from there on.

We were taken down in a lift to an awaiting bus which is manned by lovely people. They are very chatty and put you at ease straight away. The bus then takes you to the front of the plane and is risen up to the front doors, just behind the pilot's cabin.

We were given front row seats with extra leg room. The same treatment was given the other end, and on the return journey. I felt rested and happy. The Wheelchair access is free of charge.

If it wasn't for this service that is provided at most airports I would not have wanted to go abroad again, as it was too exhausting. I hope this is of help to others and encourages them to go abroad.

Thanks for reading. Della Brookman. :-)

"I don't need a wheel chair yet!!"

Recently, my husband has become 'Disabled' and I have become a 'Carer'. What rubbish! To me he is still my husband, and I am just the person who bumbles along doing my best to help him come to terms with his spastic paraplegia. So I thought I would write a letter to the HSP that other 'Carers' may find interesting.

It all started some years ago when he tripped over a bit more often than he should and fell a bit more frequently. After a couple of years of persuasion - OK I admit nagging - he went to his GP and after some prodding and poking that Doctors seem to specialise in and a couple of scans, he was told that they didn't know what it was, so it was probably FSP. Ah! A name. At last we had a name. We didn't know what FSP was, but it was a giant step forward to us. We were told that

unfortunately there was nothing that could be done and we were left to 'get on' with FSP (whatever it was).

Several years later as his walking deteriorated we started to go through the "I don't need a stick yet!" stage. This meant that I had to have a strong arm and a strong back as he leant more and more on me to help with his walking. Eventually, two acts of kindness from friends helped us to learn more of his problem and allowed us to get to the next stage. First, some close friends acquired a stick and insisted he try it out. Wow! We went from the "I don't need a stick yet!" stage to the "I'm fine!" stage, what a leap forward. Secondly, a medical friend did some serious investigations and advised us that a senior person in this field was Prof. Nick Wood of the Institute of Neurology in London. Admittedly, Nick couldn't tell us more than the other consultants regarding a cure for FSP, but he did manage to make the negatives seem more positive. It wasn't a major problem that would take Terry away from me and Nick gave positive help with dealing with some of the problems including putting us in touch with the FSP group. This proved to be a really good thing. We met people who were getting around with a smile on their faces, travelling the world and coping with the small hiccups of life on a daily basis (I know this belittles some of the trials faced, but it doesn't help to dwell too much on these). They were all happy to impart knowledge of how to make life easier. What a super group to be part of.

Well, a few more years have gone by, we have gone through the "I'm fine" stage and the "I'm OK!" stage and the "I don't need two sticks or a tri-wheeler yet!" stage and again, my arm and back took the strain as I longed for this stage to pass. But at the same time I have so much pride in my husband, a strong man who has a wonderful fighting spirit that is keeping him mobile - long may it continue. As we now realise that we can continue to travel the world, we have reached the "I don't need a wheelchair yet," stage.

My 'Carer' logic says you use all three facilities. At home - no sticks, using walls,

chairs, door handles, etc. Short walks - one stick slightly longer or uneven surfaces - choose between two sticks or tri-wheeler. Wandering around larger shops or airports, train stations, etc. - a wheelchair. (A recent food market springs to mind, when his energy levels were depleted before we actually reached the food hall). But you see, I am not the one having to face the fact that if I take the easy option too much, it will put me in a wheelchair permanently, so we jointly fight to keep him active for as long as we can.

So here we are! Still at the "I don't need a wheelchair yet!" stage. But, we have learnt to enjoy things in a different way and we definitely don't say "No, I can't do that because I'm disabled". We just look at different ways of doing things.

Patricia Reed

Regional News

Regions 9 & 10

To all HSP group members - particularly those living in regions 9 and 10.

Many of you will know me, John Morris, father of Zoe Gibson who has HSP and I organised the meeting last October at Blackburn.

A meeting is planned on Sunday October 11th 2009 at Sutton-in-Craven village hall, which was suggested in our discussion at the Blackburn meeting by HSP member Garry Petersen. In fact Garry has done most of the organising already but I have the task of inviting people to attend. Garry assures me that the hall is well suited for us with good facilities available.

We plan to start at 10.30 with coffee followed by a talk by Dr Stoppard on 'Rehabilitation Medicine with Special Reference to those with HSP'. Have lunch - we are planning a Sunday roast. Then in the afternoon to have a talk and display of mobility aids by 'Howden Hall Mobility' a company based in Keighley and to finish off with time to talk to each other and afternoon

tea. Finishing at around 4.30. We would however need to charge everyone £8 to cover costs for the day (expenses, hall hire, lunch, refreshments etc).

Should anyone wonder where Sutton-in-Craven is, it is roughly mid way between Blackburn and Leeds. It is a village just off the A629 and A6068 near Silsden, between Skipton and Keighley.

Confirmation of bookings and payments to be received by Saturday 20th September.

John Morris
Rose Bank
Ings
Kendal
Cumbria
LA8 9PY
Email joka@madasafish.com
Tel 01539 821870

OR

Zoe Gibson
11 Vicarage Road
Levens
Kendal
Cumbria
LA8 8PY
Email gib@ic24.net
Tel 015395 60096

Forthcoming Events:

Region 6 get together

Saturday October 10th 2pm onwards
Some members will arrive earlier for lunch

All welcome for lunch
The Atlantic Hotel, Porthcawl
Call Peter Bateman on 01656 788502

Region 4 get together

Saturday November 21st 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday November 28th 3 – 6 pm
Milford Day centre

Anyone interested in attending, please contact Jane Bennett on:
020 8853 4089

Region 9 & 10 get together

Sunday October 11th
Sutton-in-Craven village hall
10-30am – 4-30pm
Please see article on page 8

New Members

We welcome the following new members:

Alan Vassalli Taunton Region 4	Catherine Stewart Rugby Region 7
Anne Williams Southport Region 9	Damien & Juliet Lynch Cheadle Region 9
Carol Gittins Powys Region 6	David Adams Northern Ire
Ellie Brock Epsom Region 1	Sherrill Casburn Newark Region 8
Frederick Gill Bridgnorth Region 7	Janet Porter Tonbridge Region 1
Norma Francis Cambridge Region 5	Marlene McMahon Holt Region 5
Sylvia Ayling Woodford Green Region 5	

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

A few words from ex-chairman, David Pearce

Hello everybody, I'm back!

Well after radiotherapy and a three week stay in hospital, I'm out and about again. I now have a "care at home" package (which is nice) and believe me; I have first hand knowledge of mental and physical fatigue. Full recovery may be some time off but hey guys, what's the problem? I am happy to talk through dealing with prostate cancer at any time.

Great news! Richard Williams as Chairman. I was so boosted when he presented himself and your card to my hospital bedside on the Saturday of the conference. Thank you so much.

It's been a pleasure and a privilege working with you all over some eleven years. My sincere thanks to all committee members (and members) past and present. The input of their time, skills, personal qualities and enthusiasm to sometimes tackle the unknown, have set us on a secure, positive path for the future. Wait for it! I'm looking forward to an active participation in the years ahead and I'll be remaining on the committee.

I can't wait for Jane Bennett's next meeting at Milford and with some assistance I really hope I'll be able to attend our AGM at Leamington Spa next June.

Throughout the last eleven years, I've made so many friends who I'm keen to keep in touch with.

I look forward to meeting with you all soon.

Very best wishes,

David

Useful Contacts

	Email	Telephone No:
Richard Williams - Chairman Ash Tree Rise, Wendon Road, Saffron Walden, Essex, CB11 4HD	rushour33@gmail.com	01799 550534
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
David Pearce 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 8551 2905
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

Minutes of Annual General Meeting

Held at Trident Technology and Business Park, Warwick on Saturday 20 June 2009.
The Meeting opened at 11.00am

Present: Committee Members; John Mason, David Harris, Ian Bennett, Stephanie Flower & John Moore, being part of a total of 85 members. (A record)

Apologies were received from 35 members, including, notably our Chair David Pearce, who was presently in hospital, and in whose absence, the meeting voted David Harris as Chairman of today's meeting only. Sadly also, apologies were received from our past Treasurer, Mike Fawcett, who had originally registered his intention to come.

Minutes of 2008 AGM. Duly accepted as a true record. Proposed for adoption by Richard Williams and seconded by Eric Spalding.

There were no Matters Arising.

Committee Reports:

1. **Help-line (Stephanie Flower).** Mentioned that her Canine Partner, Frodo was now to retire from duty, as she was now pursuing patterns of help from her new dog. She renewed her offer to discuss the system of Canine Partners with anyone, and also to provide advice for those seeking it. We also need to develop a Young Persons' Group.
 2. **Membership Secretary (Ian Bennett) and Secretary (David Harris).** With the use of slides, Ian and David separately demonstrated several important features:
 - * A national site-map, showing the concentrations in Home Counties and North-West
 - * 6 Regional Meetings took place in the year, now including South Wales.
 - * 5 members were issued with Grants to purchase equipment.
 - * We have improved communications with, and developed relations in Europe.
 - * Encouragement of members to pay by standing order, duly improving accounting.
 - * Pushed Gift Aid, and claimed £400 back from HM Treasury
 - * Completion of name-change from FSP to HSP.
 - * Participation in Focus Groups with Plymouth University.
 - * A plea for people to take the responsibility of Regional Co-ordinator in areas not so led.
 3. **Treasurers Report (John Mason).** After comment that we had, during the year, succeeded with our change of name from FSP to HSP (as had been confirmed also beforehand by Ian Bennett and David Harris), and with our registration as a Charity, a fine and clear set of audited Accounts were distributed to members present, these showing a healthy favourable balance of £19,160.82. Thanks were given to Sonya Mason for her work on the accounts, and to Theo White for his work as Auditor. Unanimous approval of the accounts followed their proposal for acceptance by Eric Spalding and secondment by Petula Baker.
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Election of Officers for the year ahead.

David Pearce, having expressed his regrets as having to stand down from the Chair, was happy to continue as Executive Committee Member. Richard Williams had been nominated to succeed him as Chairman.

Position	Officer	Proposed by:	Seconded by:
Chairman	Richard Williams	David Britton	Eileen McCarrick
Treasurer	John Mason	Alison Stoten	Ian Smith
Secretary	David Harris	Lorraine Saupe	Deborah Best
Membership Sec	Ian Bennett	Lorraine Saupe	Eric Spalding
Helpline	Stephanie Flower	Caroline Begg	Maggie Gillson
Committee Member	David Pearce	Richard Williams	Peter Bateman
Committee Member	John Moore	Nigel Bulbeck	Caroline Begg

Any Other Business

A vote of thanks for all of the hard work of the past year's Committee was proposed by Peter Bateman.

The official AGM was followed by three interesting presentations:

- a) Jointly by Sally Howells, a nurse representing Coloplast Ltd and Sian Ford representing Chartercare. Coloplast is the name of a Danish producer of items for the care and management of continence/ incontinence of both bladder and bowel, and Chartercare are the company managing the distribution of Coloplast and other incontinence products. For a few hours after their talk, these ladies made themselves available to discuss the products and their issues privately with members. Their presentation was considered to be very useful.
- b) A short talk by Monica Goro, representing the Spanish equivalent to the UK HSP Group, after which Ian answered some questions from the floor, and requested that some of our members might like to volunteer to become European Co-ordinators.
- c) An overview of gene structure regarding HSP, by Dr Christos Proukakis of the Royal Free Hospital.

Once again, our thanks go to the excellent presentation of lunch and other refreshments by the Trident Technology assistants.

The Meeting closed at 4.35pm.

Construction of Minutes volunteered by John Moore