

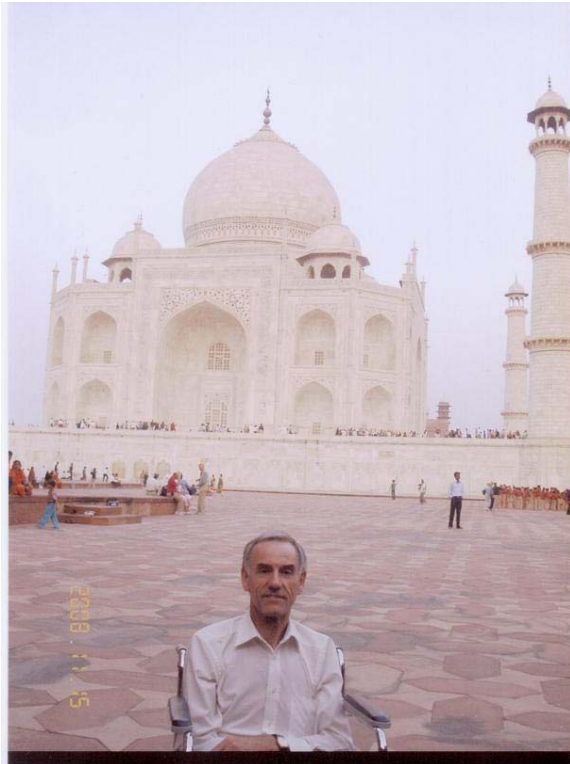
# HSP Newslink

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

**Issue 17 – May 2009**

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

## India - Work and takeaway memories



**What would you say if I said I wanted to work in India for a short time?** That was the question I asked my wife, Stella one evening as we sat down to dinner and the immediate reaction was to see her face drop and a tear appear. I have hardly been apart from my wife in 34 years of marriage let alone work abroad.

This came about as the bank I work for had a group of 10 people visit from Bangalore in

January 2008 to learn one or two of our processes and I was assisting in their training over four months as I did with another group who arrived in March but only stayed for three weeks. The bank then sought staff to go to India to oversee the set up and further training of the agents. Having worked so closely with these people / friends it became clear that this is what I would like to do and Stella supported me. I contacted one of the project managers to say I was interested but because I have some difficulty walking would it be a problem? No was the reply. Getting around the office would be the same as I am used to and drivers and cars would be available to transport us as required.

An interview followed and I was accepted onto the project for eight weeks to return home in time for my younger daughter's first baby due at the end of June. The departure date was set for mid April 2008 but first I had to receive medical clearance from an independent doctor.

With projects, delays can occur and it was not until 22<sup>nd</sup> August that a group of us from around England left via Paris to travel to Bangalore. My period of stay was now 16 weeks, although I would be away for my elder daughter's third child due in September (she had a daughter and named her Willow India).

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A concern I had because of the HSP was the urgency to pass water. Some years previously on an annual visit to the National Hospital I was prescribed a drug known as Lyrinel for this problem but didn't actually take it up. I kept the details just in case and I felt it was now appropriate to start. I was also advised to take anti malaria tablets. The side effects, and there are quite a few, are much the same for both, and yes I did have the trots and stomach problems but whether this was solely down to them or other contributing factors, I couldn't say. I did stop until things settled down and then I just took the Lyrinel every few days, which gave me the protection I needed.

Apart from work, which mirrored UK time, that is locally 1.30pm to 9.30pm, then when the clocks changed in October, 2.30pm to 10.30pm, I did manage to sight see parts of Bangalore and Mysore, a weekend away on safari seeing Elephants in the wild and a weekend away to Agra via Delhi to see the magnificent Taj Mahal and the Red Fort. I was also invited to three weddings. The people are very friendly and often asked where I came from, my name and offered assistance with steps etc. I had assistance at all the airports I encountered with no problems.

I could say so much more but am mindful of space I may be taking up.

In conclusion I had a great experience, one that I never thought would happen to me and as for HSP I certainly far exceeded my expectations. I do miss the 12 hours of daylight and the temperature ranging up to 35°C, far removed from the low or minus numbers since I returned on 12<sup>th</sup> December 2008.

John Patching

## Chairs column

Unfortunately, as many of you are aware, I have been unwell recently. I'm hoping to be able to attend the AGM in June, and will of course chair the event if present. However, I'm more than happy for other members to come forward and stand for election as chairman, whereupon I'll happily stand

down, but hopefully I'll still be able to help out as a member of our committee.

*David Pearce*

## Secretary's Spot

HSP Group's first meeting in Wales takes place in May!! Peter and Sandra Bateman, having now been to several Region 4 meetings, have arranged a meeting this month in Porthcawl on the South Wales coast so hopefully still more of our members will get the chance to meet and share their experiences, learning new ways of coping as they do so!

You will find in this issue the information about this year's AGM including forms for letting us know you will be attending. There is also a form for you to use to nominate someone to a committee position – I need to have any completed nomination forms returned to me at least one week before the AGM please.

We have not had much information from you about items in the Information Booklet which are out-of-date or need changing, but we know there are things in there which are getting out-of-date. Can I ask you to give the booklet another read-through and then help us to start the revision process by telling us of the things you have found out in the last year or so which have changed.

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

## Another great contribution!!

We usually try to let members know about all the efforts people have made on their behalf. Occasionally there are slip-ups where items fall between issues of Newslink. This item is to provide recognition to Paul Smith who did some sterling fundraising for the Group by running in the Dublin Marathon in October 2007. Paul managed his run in 4 hours 26 minutes! As a result he raised £455 for our group and his employer - Mitsubishi Electric Air Conditioning System Europe contributed £200 as well.

Well done Paul and many thanks from the HSP group.

David Harris

Secretary, HSP Group

## Useful Information

### Don't Forget Your Badges

I expect that many of you are pleased to read, in journals such as Mobilise, of increasing developments to check on the justified usage of Disabled Parking bays. However, I was recently caught-out at the Asda car park in Waterlooville, because I failed to display my Blue Badge, and so the company running the scheme left a message on my screen to tell me that I must pay a fine of £30, if paid within 10 days, or have it increased to £60 thereafter.

I made an appeal against it by sending the company a photocopy of my Badge....and I am waiting in hope for their acceptance of it. (Which I do indeed hope for, as this is a private scheme and not a police offence). So I leave you all with this message, Please don't forget to display your Badge: even when you are in a justified space.

*John Moore*

### FES Guidelines changed by NICE (National Institute for Clinical Excellence).

NICE produces guidelines about medical interventions (drugs, equipment etc.)

PCTs are required to take notice of these guidelines when forming their own policies for the treatment of patients.

Previous NICE guidelines about FES had specifically mentioned MS or Stroke patients, but not other conditions. Therefore many PCTs had followed this line and only provided funding for FES for patients with those two conditions.

The NICE guidelines were changed in February. FES is now considered an appropriate treatment in all cases where a dropped foot has a neurological cause (irrespective of actual diagnosis). This means

that PCTs will now be able to fund the use of FES for a much wider range of patient conditions where dropped foot is a result.

When we learned of this in early March, Carolyn sent a letter to her GP giving the information about the NICE changes and requesting if funding could now be provided (we had funded the equipment privately for the last two years).

In due course we got a reply saying that as the PCT would be changing its guidelines in the light of the NICE changes we would be funded as a special case until the guidelines were changed! An excellent result!

*Dave Harris*

### Family History

If my memory serves me right the inaugural meeting of the FSP Group was in 1991 at the Royal Hospital, Queen Square, London. Perhaps Tony or Stephanie could confirm or amend that. It was very well attended by members from all parts of the UK.

The meeting was opened by Stephanie Wyatt who had played a major part in bringing the group into being. Tony Glas had arranged a very interesting programme of illustrated talks with opportunity for question and answer sessions. The speakers were Dr N Wood, a specialist from Addenbrooke's Hospital whose name I cannot remember, and a lady specialist who was known to some families as she was undertaking some valuable genetic research work, sadly she died prematurely from breast cancer. At one of the afternoon sessions a member asked if we were all distantly related as it was largely an inherited condition. The specialist from Addenbrooke's suggested that if we were to trace our families back into the 1600s we would discover a common ancestor.

I became interested in this suggestion as I had been doing my own family history since the early 1970's. Afterwards it was agreed that the group would endeavour to pursue this idea. In consultation with Dr N Wood I drew up a double form on which members could record immediate family, extending families down to grandparents plus any other relevant information indicating where the

problem did or did not occur. The form was sent to all members, to be returned to me, and then forwarded to Nick Wood. There was a good response but as was expected everyone did not participate. The knowledge people had of their wider families varied considerably. I drew up some notes on guidance for anyone interested in further investigation. Those were put on the website, without my permission. The family history research scene is constantly changing and needs to be updated frequently. Three members took their lines further back but there were no indications of any relationships of any kind. Tony included the forms in his information pack and these were usually returned to me with details. Some time later I wrote to Family Tree Magazine, which resulted in three responses, two of whom later joined the group. In 1999 I contacted members who had withdrawn, but that was not fruitful. Perhaps they had discovered it was not the disorder which they had.

I suspect the practise of distributing the forms was discontinued as the numbers dwindled and it is several years since I last received any. Members may be sending them direct to Dr Wood. Early this year I was talking to Dr A C Smith at the Yorkshire Genetic Centre. I asked what the incidence of HSP was in the general population. Her reply was one in 25,000. I am not sure of the current population of the UK but it is fairly obvious that there must be a lot more people out there affected by HSP who have no knowledge of the existence of our Group. I am not sure what current group membership is, but multiplied by 25,000 I think we would reach a very small number.

One of the problems in identifying occurrence in earlier generations is that it is only comparatively recently that advances in identifying disorders of the nervous system have been made. Going back in time, death certificates give very different causes of death and problems from what is recorded today. If anyone is interested in family history I can recommend it as an engrossing and rewarding, sometimes frustrating hobby. For anyone with computer access there is a vast amount of information readily available but it

is essential to treat it with care and do thorough investigations.

Audrey Town

In response to Audrey's letter, I have to confess that it was me who stopped sending out Family Tree forms to new members, because I'd received absolutely no feedback that anything was being done with them. However, on my recent visit to the National Hospital, I discussed this with them and they've requested that we start sending them this information again. Consequently, recent new members have been sent a "Family Tree" form to complete, but as yet, I still haven't had one returned to me. When I receive these, I'll forward them to the National Hospital.

*Sorry – Ian Bennett*

## Members' Letters

Hello everyone!

I was diagnosed with HSP in the early 1990's after the birth of my daughter.

I was so traumatised after being diagnosed with HSP, my marriage ended as well. I just can't begin to tell you how low I became.

My daughter is now 18yrs old, my little treasure, I brought her up on my own, she has never known her father, he abandoned her. My mum and dad were a tremendous help to us both.

I've spent a lot of these 18yrs feeling angry, buckets of tears, who would want me, I can so relate to Della Bookman's article in February's newslink. I had to write this article to you all in response to how it made me feel.

I met Kevin 2yrs ago and he is just terrific. He sees me not my affliction, I'm so comfortable with him. We have so much fun, I'm actually living again. Love conquers all; I want you all to think about that!!

*Christine Snow Region 10*

## Don't let HSP slow you down!

On a recent visit to a local hostelry Dave and I met Ian Bennett for drinks and lunch. After a couple of excellent pints of Piddle (the name of the beer) we made our way homewards. After a few miles we suddenly realised we had not paid for lunch! After a hurried stop of two cars at a convenient junction way down the road, we HARRISES, having more time that day, went back to pay and make our apologies.

Who would have thought that we could still “do a runner” with our condition?

*Carolyn Harris*

Dear Ian,

After Madrid we met a second time in Braunlage, and I hope you remember me. I want to tell you a bit about my relationship to HSP: I talk to my HSP and tell her that she must attend me in every situation of my life. Last year I went sailing to the Netherlands, and she had to come with me onto the sailing boat (I have some sailing licences). And we managed sailing together. Since I have been riding for about 45 years she must sit with me together on horseback. I bought a young horse for riding therapy, not only for me, I lend it to the therapists. And my HSP must swim together with me. You see I do a lot together with her and nobody can tell me "you can't do this or that with your disease". I can! And I will continue doing plenty of things, together with my HSP because she won't leave me alone. And every year I am on holiday in different countries, last year on Malta and Mallorca, this year I will go to Poland and Russia since I speak Russian very well. I don't live totally alone, my HSP lives with me. Male friends dropped me because I am not able to walk a long distance. I am happy alone with me as well, and I am still working a bit with my music scholars and with my learners in prison - they learn English and the Russians there learn German, and I teach Word there as well.

So I hope you got home safely, and perhaps you will answer me. I would be happy.

All the best to you

*Cecilia*

Hallo,

I am Andrea from Bavarian in Germany.

So, at first: My English is school-English and this time is twenty years ago. Sorry for my mistakes!! I hope you understand me!?

My little daughter (she is seven years old) and I (35) have also HSP. I think it's time to say HALLO to the other people with HSP in Great Britain.

The visit from Dr. Swain included Ian Bennet was very important for us!! Thank you for your visit!

Together we will go the street to our together finish!

Best wishes from Germany

*Andrea Kergl*

Ian

At a time when I have been forced into questioning integrity and, alas for me, counting every penny, I have found myself giving you £15.00 and begging the question – why?

I did actually volunteer over the phone for region co-ordinator but wasn't taken up on this. I assume that I am not important enough or “the right person” – I wonder.....If I had expressed an interest in flying, would it have been different?

So yes, a refund would actually be welcome and in my humble opinion appropriate.

**I was disappointed that the Group did not help this particular member and I have returned their subscription in full with our best wishes.**

*Ian Bennett*

## David McKen

It is with regret and sympathy that I inform you of the recent death of David McKen. David was one of our region 1 members from Hythe in Kent, and passed away on December 3rd following an operation. David and his wife Jennifer really appreciated the support, particularly from Stephanie Flower over the telephone, and looked forward to receiving and reading our newsletters. David was also looking forward to getting more involved in Group activities. I'm sure you'll all join me in offering our sympathy and thoughts to David's wife Jennifer.

# Regional News

## Germany

You'll probably have noticed a couple of letters from members of the German HSP Group. This is a result of me being invited to their AGM on Saturday 25<sup>th</sup> April and meeting many lovely people.

The German group now has 500 members and a very impressive 250 people attended their AGM.

I travelled with Professor Ian Swain from Salisbury Hospital and Ian gave a presentation on the use of FES as a treatment for people affected with HSP. This presentation was very well received and the following morning Prof Swain managed to assess nine of the German members to check their suitability. The result of this is that the German group is very impressed with FES and are now going to push for its approval as an approved therapy for our condition.

While I was there I learnt that in Germany everyone has private health insurance. This means that if an individual needs a wheelchair, they get one. This wheelchair wouldn't be bottom of the range as most people seemed to be supplied chairs which are in the €2000 region. Health insurance also ensures they get physiotherapy regularly and twice weekly seemed an average to the people I spoke to. When FES is approved, this treatment will also be provided by the health insurance company.

With the help of an interpreter, I nervously gave a 15 minute presentation on the UK Group and how we operate.

It was an honour to be present and I can't thank the meeting organisers enough for inviting me. I'd also like to give special thanks to Renate who not only translated my presentation, but was always on hand to ensure that my lack of knowledge of the German language was never an issue.

Ian Bennett

## Region 4

On Saturday 11<sup>th</sup> April 25 members met up at the Dartmoor Lodge Hotel in Ashburton, Devon.

We had no speakers planned, although Peter Bateman stood up and entertained us for several minutes. Peter is one of the four members who we are delighted to welcome from South Wales. Peter and his wife Sandra have now attended at least three of the West Country gatherings, and on this occasion we had the pleasure of welcoming new members, Tony and Angela Barnicoat, also from South Wales, and look forward to seeing them again.

A raffle took place later in the afternoon and raised enough funds to pay for the meetings coffees and contribute to group funds.

At our next meeting, which will take place in October or November, I'll endeavour to get Jane Grose to update us on the results of the "Focus Groups" that took place in January, in connection with the work being done for us by Plymouth University.

*Ian Bennett Region 4*

## Region 6 (Wales)

We shall be holding the first area meeting of region 6 in South Wales on Saturday 16<sup>th</sup> May in the Atlantic hotel on Porthcawl seafront. The meeting will start at 14:00 but if you wish to meet for lunch before the meeting we shall be at the hotel from 12:00 lunch at 13:00.

All members are welcome please contact me if you wish to attend so I can give the hotel an idea of numbers.

Call Peter Bateman on 01656 788502  
email: [pete@peterbateman.co.uk](mailto:pete@peterbateman.co.uk)

The Atlantic Hotel  
Seafront  
Porthcawl  
CF36 3LT  
Tel: 01656 785011

Website [www.atlantichotelporthcawl.co.uk](http://www.atlantichotelporthcawl.co.uk)

# I am my own best friend

Some of us feel as though we are not treated as a proper person. Obviously, this is not because of our skin colour, ethnic background, gender or age. Usually we are treated as we expect to be treated, so our condition may be intertwined with our view of what we are. Self esteem is not a genetic trait, but an environmental and psychological one. If we feel negativity about ourselves, we should realise that it is only one side of our coin. All coins though have two sides. Let's flip our coin and find our upbeat side. Once we find it we will be treated accordingly. This is a direly difficult thing for some of us to do. We have been brainwashed, by ourselves or our circumstances, into portraying our bad side. Since negativity is bad for anyone, lets talk about how to overcome this.

One magic way to overcome negativity about oneself is to come up with a list entitled I AM. It is inherently impossible for a person to complete the words 'I am' with a negative subjective completion. Who, after all, can say 'I am dishonourable', 'I am a liar', or 'I am a thief'? In addition, roles should be ignored when we've come down to listing what we really are. Roles can be things that include things like political affiliation, job title, religion, marital status, nationality, family size, leisure pursuits, and the like. Those things say nothing about what the person is.

Self awareness is invaluable to humans, and awareness of our upbeat side forces that side into dominance. We invariably are treated how we treat ourselves. If we can each be our own best friend, depression will get interred. Since we each have to live with ourselves, being our own best friend is chicken soup for the soul!

A disabled person, the author of this article, knew she was a nonentity. Her brush with death took her grit right away from her. She, at age 41, had left her job without notice, left herself by sustaining a massive brain injury, abandoned her offspring, was removed from her country, lost that needed quality of friendship, had nicotine withdrawal and went through menopause. This person who felt the lowest of low found the I AM exercise so rehabilitating, she wishes to share it with you. This person, who was declared a vegetable, by the Jaws of Life, came up truthfully and easily with the following writing about what she is. No psychiatrist could have done for her what this writing did for herself. This cure was even free!

I am reborn as a new person from the time  
of my brush with death

I am able to ask questions anytime and  
anywhere

I am great with kids and pets

I am unique

I am witty

I am kind

I am a sharer

I am intuitive

I am a truth teller

I am insightful

I am not the age I appear to be

I am unforgettable

I am comfortable around anyone I haven't  
been married to

I am a good communicator in writing

I am understanding

I am a friend

I am free

I am an inspiration to anybody

I am able to find the sun behind the darkest  
cloud

I am proud of coming through to where I am

I am liked

I am analytical

I am able to cope

I am glad I live with me

**I AM**

**We are each in control of ourselves and  
people treat us as we expect to be treated.  
Let's put our best foot forward and be our  
own best friend**

Thanks to Sue Dent for this interesting  
contribution.



## Forthcoming Events:

### Region 6 get together

Saturday May 16<sup>th</sup> 2pm onwards  
The Atlantic Hotel, Porthcawl  
Call Peter Bateman on 01656 788502

### Mobility Roadshow

4<sup>th</sup>, 5<sup>th</sup> & 6<sup>th</sup> June 2009  
Kemble Airfield near Cirencester,  
Gloucestershire  
Open daily 10am free admission and parking  
[www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)

## New Members

We welcome the following new members:

Donna Scraggs  
Liverpool  
Region 9

James Gregory  
Sidcup  
Region 1

Philip Love  
London  
Region 2

Sam Allan  
Wolverhampton  
Region 7

Graham Bryce  
Towcester  
Region 8

Jenifer Crosby  
Halifax  
Region 10

Roland Crothers  
Somerset  
Region 4

Shirley Hicks  
Plymouth  
Region 4

Sue Dent  
Worcester Park  
Region 1

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

## HSP flying day

Friday August 7<sup>th</sup>  
Lasham Airfield Hampshire  
½ hour local flight 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

## Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	<a href="mailto:pearcey david@yahoo.co.uk">pearcey david@yahoo.co.uk</a>	020 85512905
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	<a href="mailto:dave@vadcar.org.uk">dave@vadcar.org.uk</a>	01305 772286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	<a href="mailto:john@jrmason.demon.co.uk">john@jrmason.demon.co.uk</a>	01225 761788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:FSPgroup@aol.com">FSPgroup@aol.com</a>	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	<a href="mailto:ian.bennett@tesco.net">ian.bennett@tesco.net</a>	01202 849391
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 88534089
John Moore – New Member Co-ordinator	<a href="mailto:john@moore108.orangehome.co.uk">john@moore108.orangehome.co.uk</a>	02392 592784
Peter Bateman – Region 6 co-ordinator	<a href="mailto:pete@peterbateman.co.uk">pete@peterbateman.co.uk</a>	01656 788502
Michael Cain - Region 9 co-ordinator	<a href="mailto:Mikeregion9@fsmail.net">Mikeregion9@fsmail.net</a>	0161 456 7531
Liz Ferguson - Region 11 co-ordinator	<a href="mailto:lizferguson1@ntlworld.com">lizferguson1@ntlworld.com</a>	01415 779695
Colm Treacy Neurogenetics Clinical Nurse Specialist	<a href="mailto:colm.treacy@uclh.org">colm.treacy@uclh.org</a>	020 76762115