



HSP Newslink

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

Issue 26 – May 2012

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

A Little More Time to Spare



As getting around was becoming more difficult, I stopped work half way through 2007. I have always enjoyed getting around out of doors and so I set out to try and get round to seeing as many gardens in the Kent, Sussex and Surrey area while I was still able to. I don't go anywhere very fast now but hey, what's the hurry?

As this condition started to take effect, I tried to travel around the world and see the places that appealed to me. As that has become more difficult, I never cease to be amazed and delighted by the beauty of what we have on our own doorstep in the British Isles.

I have become conscious of how important my sight is to me to be able to enjoy these things and for that reason, have always felt a particular sympathy for people who have lost or who are losing their vision. About 18 months ago, I rang a local blind charity to see if they needed volunteers for anything. I was quite surprised to hear that they were looking for guardians who could help blind people make trips to the theatre, to cinemas and museums. I explained that with my disability I was more likely to be a hazard than a help! They thanked me for calling, took my details and said that they would contact me if any other opportunities arose. Only four days later, I received an email from RNIB asking if I'd like to help with something called "Tele Befriending?" This involves being something of a referee as six or so people from around the country meet up for an hour to have a conversation over the phone. The charity tries to get

people of similar interests in the same group and for many of these people, the hour of conversation that they have may be the only real contact they have with the outside world in that week. I may need to play no part at all but I am there to help things along if need be and to stop war breaking out if things somehow become a bit heated between some of the parties! I have found that hour, each Tuesday morning, to be great fun but more than anything else, I have enjoyed the lovely positive attitude and nature of these folk, dealing with their disability.

It is that same attitude I so much enjoy seeing among our own group when we get together for our meetings at Milford. The beaming smiles on faces as acquaintances are renewed. I know that you'll all want to join me in thanking Jane and Mike for the terrific effort they put into setting up these meetings and for the interesting speakers who are so often there to have something to offer. Well I have already planned my next trip, so I look forward to seeing you at the next meeting.

Best wishes, John Williams

Chairman's Column

As you will no doubt be aware, the price of postage is rocketing and postage costs are one of our major expenses. If you are reading this Newslink and it arrived on your doorstep, please consider having future issues delivered by email. If this is an option please let me know. Up until now it has cost 58p to send each newsletter and this has now gone up to 69p which may not sound a lot but bear in mind we currently post 200 newsletters. Emailing them is of course free. Those of you who have received this by email, thank you for helping to keep costs down and please remember to let us know of any email address changes.

A few years ago I created a Facebook Group called 'Hereditary Spastic Paraplegia's Unite'. As with all such Groups it took a while for it to become well utilised but it now has in excess of 100 members and lots of useful advice and information is shared. If you use Facebook and you're not already a member, please consider joining. We have even had

people discover the Facebook Group before they discover the Support Group and this is certainly the case for one or two of our newest members.

It was a great pleasure to see everyone who attended the recent meeting in Ashburton which was the 10th anniversary of such events. We had a great turnout of 45 including a number of people who were at the very first Devon get together back in 2002. I was very touched by the cards I received and particularly the comments within. It's been a pleasure organising these meetings. Witnessing the friendships that have developed and the support that individuals offer each other, makes it very worthwhile. A big thank you has to be passed on to Dianne and Trevor Crouchen who are the proprietors of The Dartmoor Lodge Hotel. They always bend over backwards to do anything they can to make our weekend more enjoyable.

Please read the article titled 'HSP Horse Racing'. This describes an event which is the idea of Maurice Charge who is a relatively new member. Maurice, who works in the racing industry, has had the brainwave of raising awareness' of our rare condition by sponsoring a race which will put HSP in the title of the race. Thank you Maurice, I'm certainly looking forward to an enjoyable evening at Sandown Park and I hope there'll be a few other members present to enjoy the races. What a great way of raising awareness and fundraising.

Following the sad death of his wife Joy last December, Paul Utting has recently very generously donated the group two single channel FES Units. If anyone is considering FES and particularly anyone who's been declined funding, it could be that we can now help lower the cost. If you attend clinic at Salisbury Hospital with one of our units on loan, you'd only have to pay for the cost of treatment, and not the cost of equipment. It could even be that the Group could help with some of the therapy costs with one of our grants. I have been in communication with Salisbury FES team concerning this and they'll certainly assist all they can. If this is of interest, please contact me and thank you Paul for this equipment. I hope we can make good use of it.

I hope you are able to join us at our AGM on June 16th. You'll read more about it in this Newslink and you'll notice we have three interesting speakers. There will also be time to chat to old friends and make new ones. Please let us know if you are attending by returning the form that you have or will shortly receive to John Mason. We have fixed the price at £7-50 per person which includes a buffet lunch and teas, coffee's and cakes throughout the day.

Ian Bennett

HSP Horse Racing

Fancy a night at Sandown races?

The HSP group has a race sponsored at Sandown on the 24th May, which is an evening meeting.

The race will be titled 'The Hereditary Spastic Paraplegia Awareness Handicap'. It is aimed at making our condition aware to the general public, similar to how MS was not understood in the 70's to most people, but of course people now are aware of that condition.

We have free tickets available for the evening and will be issued on a first come first served basis, we also have access to a box, depending on the response, will be a pop in meeting place, where a finger buffet will be available, and a cash bar.

We'll also be able to select 'the best turned out horse' pre race, and someone will be selected to present the trophy to the winning owner of our race.

There is the opportunity for us to run a collection at all the exit points, but here lies a small problem, for we need a team of collectors on a volunteer basis, who will be standing at the points from the end of the second last race, so if you know of any able bodied friends /family who could help us here, for it will be a great opportunity to raise cash for the group.

All this is at NO cost to the group (apart from your losses on the horses!) and needs your support if possible.

Please contact Ian Bennett to register your interest and help if possible.

Maurice Charge

Good old Mike!

As you will have read in an earlier Newslink, Mike Fawcett died in August last year and we have recently become aware that he left a donation to the HSP Group in his will.

He was a founder member of the HSP Group and was an active member of our committee. According to his fellow committee members he was a hard worker, passionate about moving our charity forward and a pleasure to work with. He and David Pearce spent many hours together looking for suitable venues for AGMs. He was Treasurer until 2006.

Although he had increasing difficulty getting around he wouldn't let this hold him back and made the effort to attend meetings as far away as Devon and Surrey, a long way from his home in Skipton, Yorkshire. He certainly enjoyed meeting fellow members and his great attitude inspired many of us.

It was typical of Mike to have thought of the Group in his will. We have added his donation to the fund allocated for research into HSP.

John Mason

Useful Information

At our recent Region 4 meeting a member drew my attention to the following device which looks a very simple way of correcting dropped foot. If anyone has any experience of this please provide some feedback.



The **Boxia Ankle Brace** is suitable for Drop Foot, Peroneal Neuropathies, Dysfunctional

Gait, spastic paralysis and circulatory/sensory disorders.

The 2-part wrap-around design of the Boxia Ankle Brace makes it a dynamic drop foot splint. The Boxia Ankle Brace features a non-slip section which fits between the tongue of the shoe and the shoe laces, making the brace discreet and comfortable. The sections of the Boxia Ankle Brace are linked by an elastic strap which can be adjusted depending on the level of support required. The Boxia Ankle Brace also features localised gel padding for comfort, and is lightweight and easy to fit. The *Boxia Ankle Brace* produces a dorsiflexion when stepping off the foot, as indicated in flacid paralysis.

<http://www.healthandcare.co.uk/foot-drop-supports-and-afo/boxia-ankle-brace.html>

Members' Letters

Dear Editor

Brian Day's letter in the previous issue got us both thinking about the nature of HSP.

Without order there is chaos. We live in a social structure where everything and everyone is sorted and pigeon-holed. It is a natural human response that when we suffer from any medical condition, we need to put a name to it. There is almost a sense of relief when at last the consultant puts a name to that amorphous mass of symptoms, and calls it 'Hereditary Spastic Paraplegia'.

At the very first meeting of the HSP Group in The National Hospital in the early 90's, there was a tangible sense of shared identity when members, for the first time in their lives, met others who shared the same symptoms, experienced the same difficulties, and walked the same walk.

But HSP is not that straightforward. Very quickly we learn of early on-set and of late on-set. We learn of recessive inheritance and dominant inheritance patterns. We learn of X-Linked HSP, and an ever growing number of gene mutations leading to HSP. We discover that no two cases are the same, that even within families where two siblings have HSP, their symptoms can be completely different.

We have three sons all of whom suffer from early onset HSP, recessively inherited. The last was born before the first was diagnosed. One of the extra risks for early on-setters is the possibility of damage to neighbouring genes during development; this leads to Complex HSP. All our boys have this Complex form. In the case of our family, the most striking symptom has been a gradual degradation of brain function. Initially this was identified in childhood as having poor spatial awareness and some learning difficulties. In adulthood this has developed into a near complete loss of reasoning and short term memory. In terms of physical disability, we do not know how much further things can go; at the moment our eldest son can not move at all, and is almost without speech.

Our purpose in writing this letter? There are no norms with HSP, there are no predictable patterns, and there are no certainties. We just wanted to add a small piece to the jigsaw of understanding HSP. We are always so inspired to read about how resourceful HSP members are in the ways that they cope with this multi-faceted condition.

Tony and Judi Glas

Dear All

I have been a member of this group for seven years now. When I first joined the group I spoke with Stephanie Flower (Help Line) and she gave me Ian Bennett's telephone number and it all started there.

He asked me if I would be attending the meetings but I told him I didn't drive. He told me about another member of the group that may be able to help and that is how Christine Snow and I met and still are very close friends who understand each other.

If it hadn't been for Ian (Ben as he is known by to some of you), this would not have happened.

About four years ago he came up to Doncaster and I went down there and had a lovely weekend together.

A year or so later both Ian and Christine came to Leeds and again we had a lovely time.

He kept asking us when we were both going to come to Devon and spend some time with him and all the others who attend his Region 4 Meeting.

With this being the 10th Anniversary of his having these meetings what better opportunity to be there and share it with them.

We both had a lovely time and it was great to see him and everyone else in a more relaxed environment.

We were made really welcome and people couldn't believe that we had travelled all that way, but it was well worth it and don't know why we have not done it sooner.

Many thanks to everyone for making our weekend a very enjoyable one.

Finally, I want to say a massive thank you to Christine for taking me there as it was a long haul and without her I wouldn't have been able to go.

“HERE'S TO THE NEXT TIME”

Deborah Best (Region 10)

Dear all,

I was suffering from trips and falls but my main issue was painful cramps/spasms and twitching in my legs in the evenings and during the night that was preventing me from sleeping so I started to visit my GP. I was referred to a neurologist locally who arranged for a whole battery of tests, twice, and during this time I was prescribed lots of drugs starting with quinine and on through amitriptyline, gabapentin, pregabalin, nortriptyline and baclofen. None of which really helped and some had unacceptable side effects including the baclofen which made my legs weaker and affected my personality. At this stage, still without diagnosis I was referred to Professor Shaw at the Royal Hallamshire Hospital in Sheffield.

My elder (half) sister was diagnosed in the early nineties with HSP and during my first consultation with Prof. Shaw she diagnosed me with HSP too (she asked me many questions about issues I had that I hadn't even realised were linked with the condition) and it was a relief to be finally taken seriously. My mobility, whilst affected, is only minimally so

and my health issues are more with the pain in my legs, bladder and bowel problems. When my legs hurt at night, I can't sleep. When I'm tired my legs hurt more and the circle gets vicious. Professor Shaw prescribed Tizanidine and I gradually built up to 8mg at night and have been taking that for well over a year. It has made such a vast difference to me, I'm rested, less tired and low spirited and more able to cope with the extra hurdles that HSP, other health issues and life throws at me. My legs are much less stiff during the day, my mobility is better and although I had a bad fall yesterday, it was an unusual event instead of a frequent occurrence.

I've had to be constantly determined not to be fobbed off by the NHS and have received some excellent care from the local urologist, bowel surgeon and his team and will remain under the excellent care of Professor Shaw and her team. I am currently awaiting an appointment to see a neuro-physio in York (referred by the team at the Hallamshire) because there are none locally and the physio here just gave me a sheet of exercises that were more painful than improving.

I have seen how HSP can narrow the sphere of your life and the impact it has mentally as well as physically, my sister is a constant comfort to me and is brave and strong in ways she often can't see but I would urge everyone not to just put up with the many side effects of the condition and to fight for the treatment that best suits you and your symptoms.

Thank you and all the members of the group for information and inspiration.

Best regards

Melanie Burnside

Dear Editor

My name is Eric Spalding and I was diagnosed with HSP when I was 45 years old, some 26 years ago. I hasten to add that I had been suffering with the condition a few years prior to this but at that time the GP's did not recognise the condition.

Although I also suffer with Asthma, (an early onset from the age of three) I was actively involved with school sports representing the school in football and other annual sporting

activities. I hasten to add that my brother who is two and a half years older than me also suffers with the same conditions and both manifested at the same age times as I experienced. In his youth he also enjoyed sporting activities and was called upon for representing his country for active duty where he was posted in the Middle-East for two years. During this time he was promoted to the Military Police (the red caps) which he thoroughly enjoyed.

My mother who was the carrier of our condition, passed away before she knew that she had passed the condition to both my brother and I. She would often talk about her family relatives all being 'cripples' and how lucky she was to have a fit family. At this moment in time it has not affected the female members of the family but the analysis of our genes does not read that promising at 50/50.

I currently use shoes with callipers to assist with keeping my feet and legs as straight as possible, but a recent visit to the Orthotics clinic have said that I now need to wear boots with double callipers. This has dashed my hopes to wear callipers similar to those worn by Ian Bennett.

My HSP has affected most of the muscles below the waist and I am constantly being reminded of the problems. However if I were to choose between a late onset against an early onset I would choose a late onset every time. I did enjoy life very much before my onset which I could not have performed with HSP during those times.

I thought I recognised the picture of Brian Day (region 1) from the picture in the previous HSP Newslink and this was confirmed when we met at the recent Milford meeting --- it was good meeting him again. Our first meeting was a few years ago at an annual swimming gala for disability members and I am pleased to relate that I won both county and national in the event.

I do agree with Brian that we can do without sympathy and it is important to keep involved in activities to meet and laugh with people that takes ones mind from HSP.

Eric Spalding Region 1

Regional News

Region 6

Due to a busy first half year and the AGM in June I shall be holding a District 6 Wales meeting on Sunday July 15th at the Seabank hotel in Porthcawl (lets hope we have some sunny weather).

The hotel can provide Sunday lunch at £7.50 per head for any wishing to join us for lunch. The meeting will start at 2pm in the front guest lounge.

The bar will be open for tea/ coffee during the meeting please let me know if you wish to attend so I can inform the hotel of numbers.

Best wishes

Sandra and Peter Bateman

Regions 1 & 2

Managing our diet to help with the fatigue we often experience (especially in the afternoons) and needing energy when we are walking but not always being able to exercise to burn the calories, can be difficult.

Magalie Paillard, a Nutritionist from Nuffield Health, joined us for the Milford meeting, and guided us through foods which could be included in our daily diet. Many were pleased that a glass of red wine with ones meal was encouraged.....

Understandably having to move away from our favourite comfort foods could be difficult, but the inclusion of certain foods or slightly more of the savoury protein and vegetable types and less of the sugary carbohydrate ones could be useful.

Magalie's presentation was interactive. As much as she asked the questions, many questions were asked by the group (special thanks to Brooke).

To finish her presentation Magalie made a smoothie with soya milk, fresh strawberries and pea protein. She also brought some Bounce. Bounce are high energy balls, with flavours such as Cashew and Pecan. These Bounce balls are made from foods delivering

natural energy, made with a selection of nuts, oats and seeds; all the type of protein fibre foods which give us sustainable energy.

To ensure individual concerns were addressed she spent time with members after her talk.

Magalie will be e-mailing her presentation and a few recipes for us to try.

On receipt of this I will be sending out copies

Exercising and keeping our muscles stretched can be difficult. I know some members, as I do, take Pilates classes and previously we have had a presentation from Excite. In November, Jenny, a Yoga teacher who teaches Yoga to the disabled, should be joining us to do some chair and standing Yoga.

Wishing you all a good summer.

Best wishes, Michael and Jane

Region 4

Ian welcomed everyone to our meeting making a special welcome to our new members, Rob Edwards, Barrie Moss and Gail Calvert. He then suggested that receiving the newsletter by email would be helpful especially with the new postal costs. We were also encouraged to use the Facebook group 'Hereditary Spastic Paraplegia's Unite'.

Ian then with us remembered when our group first started which was with a meeting at the Exeter Holiday Inn in 2002, followed by the Barn Owl Pub in 2003. In 2004 the meetings were moved to our present meeting site at the Dartmoor Lodge Hotel, but it was not owned by the same people then. Since Diane and Trevor Crouchen have taken over every consideration has been taken to make us welcome and very comfortable.

Christine Snow and Debbie Best were welcomed having come all the way from Doncaster and Leeds. As usual of course there is the 'Welsh Invasion!' Of course they are also very welcome to join us. Many thanks were also given to John Mason and David Harris for all their very hard work as treasurer and secretary respectively.

Ian was telling us that as a result of gaining a flying scholarship for disabled people, he had

flown since 2005. Since then Caroline Begg and Della Brookman have also learnt to fly. Only about eight individuals are selected each year for the scholarship and this year Lorraine Saupe and Mark Thomlinson are up for selection, and at the time of our meeting were in the last 24.

As Ian said many of us will take the opportunity to visit other places in the South West while travelling to the Ashburton meetings.

At this point Eileen and Kathleen who are amongst our Welsh friends, advised us that we had raised about £1500.00 with our 'Sponsored Welly Dance' and thanked us all for our efforts and support. Various people were given awards for their extra effort during this occasion including Eileen for such a fantastic idea.

Ian then told us about some new crutches called 'SmartCrutch' which come in bright colours and the Boxia Ankle Brace (see Useful Information) which is a simple device to help combat foot drop.

Thanks came from Christine and Debbie to Ian for starting their very good friendship.

Time then for tea and a chat during which Lorraine as always very busy came round selling raffle tickets for a successful raffle and took photos. More memories recorded towards the next ten years. Although some of our members left after tea the rest were more than ready to stay for dinner, the odd drink or two before bed. Breakfast the next morning is never a rushed affair as we all feel so comfortable with our friends, not having to make any excuses for slow movement etc. As always a very welcome meeting and I for one look forward to seeing as many of you as possible in October.

Jennifer Gill Region 4

Forthcoming Events:

Region 4 get together

Saturday October 20th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Region 3 Meeting

Saturday August 11th 1pm – 4pm
The Orange Tree, Hitchin
Call Della Brookman on 07513004040
or Ian Kitchen on 07540476735

Afternoon tea Regions 1 & 2

Sunday November 18th
Milford Day centre
Contact Jane Bennett on: 020 8853 4089

Region 6 (Wales) Meeting

Sunday July 15th All welcome
The Seabank Hotel, Porthcawl

Call Peter Bateman on 01656 788502

HSP Support Group AGM

Saturday June 16th
Trident Technology and Business Centre
Leamington Spa

The Mobility Roadshow

East of England Showground, Peterborough
21st, 22nd & 23rd June
www.mobilityroadshow.co.uk

New Members

We welcome the following new members:

Robert Edwards
Havant
Region 1

Linda Ryan
Sheffield
Region 10

Tracey Williams
Swindon
Region 4

George Lunn
Spalding
Region 8

Abbie Norton
Truro
Region 4

Jane Rowe
Cheshire
Region 9

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.

HSP Support Group 2012 AGM Details

Saturday 16th June

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

- 10.00 Coffee & Welcome.
- 10.30 AGM
- 11.00 Coloplast – An outline of their services and a focus on Peristeen
- 11.45 Break
- 12.00 Professor Jon Marsden - Effects of temperature on neuromuscular function in spastic paraparesis
- 1.00 Lunch
- 2.15 Professor Andrew Crosby - Research Advances in Hereditary Spastic Paraplegia
- 3.30 Coffee and open forum
- 4.30 Close

Coloplast will remain with us for the day to speak to members privately and offer any help and advice on continence issues.
