



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

Research project – What effects do hot and cold temperatures have on leg function?



Jon, Alan and Amanda perfecting the research!

Volunteers needed!

An exciting research project at the University of Plymouth is looking for volunteers who have HSP. The project will be looking at the effect of temperature (hot and cold) on nerve and muscle function in the legs.

This will involve 2 visits to the University of Plymouth where we will be cooling or warming your lower legs and looking at some measurements of how this affects your nerve and muscle function. Each visit needs to be separated by 24 hours and each one will take 1-2 hours. Travel expenses will be reimbursed.

The research team (Amanda Austin, Prof. Jon Marsden and Dr Alan Hough) are aiming that the research will help us understand more about what happens to the nerves and muscles in the legs both when it is cold and hot. We hope to then look at treatments that could be used at home or by physiotherapists to manage these effects. We are hoping to start the project in March 2011.

This project has been designed in partnership with members of the HSP support group and is funded by the Chartered Society of Physiotherapy charitable trust.

If you would like to receive an information pack and are interested in taking part please contact Amanda Austin at amanda.austin@plymouth.ac.uk or call her on 01752 587995

Chairman's Column

Happy new year to all members. I hope you all managed to get through that ridiculously icy December without too much discomfort. Let's hope that the rest of the winter is a bit kinder to us.

At our last committee meeting in November, Simon Hubbard was co-opted onto the committee. Simon has been doing some great work for the last 12 months in communicating with HSP researchers and consultants. This work has improved our knowledge of what HSP research is being conducted and will I'm sure result in some interesting presentations at future AGM's. I know Simon will be a very useful member of the team in his role as Research Liaison Officer and it is a pleasure to have his help and commitment.

For several years, physiotherapists have been amazed that I don't suffer with back pain on account of my gait and particularly my waddle. Unfortunately my time seems to have come and for the last few months my back has been stiff and painful, particularly immediately after sitting in a chair or car for a lengthy period. A few weeks ago, my youngest daughter was using crutches because of a temporary injury, and I decided to give the crutches a try. Both myself and my family were amazed at the very obvious

benefit they gave me. They stop me waddling and while I used them I didn't feel the back pain at all.

I have been seeing physiotherapists recently both at my local hospital and at the Salisbury FES centre and the common conclusion is that the only way to stop my back problem is to improve my gait. For this reason I have now purchased a pair of crutches and I use them most of the time. As some of you know, I am, and always will be a huge fan of FES but I find it strange that I've been using FES for nearly 10 years, but have only just discovered how much crutches help. Sometimes we seem to go for hi-tec before trying the basics. I'm currently using crutches and FES for my dropped foot simultaneously and I'm confident that the resulting improved gait will cause my back problem to disappear.

If any of you haven't tried crutches before, I would strongly recommend it. There are some available on eBay that are slightly more acceptable than the NHS ones we can all picture. I have recently bought myself a back pack in the New Year sales which I find very useful because using crutches prevents me from carrying anything in my hands.

I have suffered from bloatedness and constipation for years and I believe that this is definitely attributed to HSP. I've spoken to many members who are affected with similar problems. I've recently learned from the advice of another member that a small portion of walnuts every day significantly helps with these uncomfortable issues and I would urge anyone to give it a try. I'm not a walnut lover, but I hardly notice three or four of them crumbled up in my porridge every morning.

I'm looking forward to the next meeting down in Devon on 26th March. I'll be bringing my wellies and taking part in the sponsored wellington boot dance. I'm sure it'll be a great laugh and we'll raise some useful funds while making fools out of ourselves. Thank you Eileen for organizing this unusual event and if you'd like further information please contact me.

One of our projects this year is to approach some trust fund organizations for some major

funding that we'll be able to contribute towards research. This is ongoing and I'd like to thank the committee and particularly John Moore for their hard work with this. Hopefully we'll have more on this at our AGM on June 18th.

Following our recent campaign to request members to consider receiving newsletters by email, a further 50 have signed up for this, saving the Group considerable funds, time and effort. This is very much appreciated and anyone else who is happy to receive future newsletters electronically, please let me know.

Apologies if this edition is a little shorter than usual, but I'm keen to get the next issue circulated well before June so that it can include a full AGM agenda. As always, any interesting articles for newsletters are much appreciated and thank you to those who have contributed to this issue.

Finally, in the previous edition, I forgot to thank members who've been forwarding their used postage stamps to Phil Burton. I know Phil has now raised significant funds for the Group thanks to your efforts. Thank you Phil for pursuing this.

I look forward to seeing many of you at future meetings.
Ian Bennett

Secretary's Spot

Can I start our first Newslink of 2011 with a wish that you all have a happy new year!

Are you one of those who find the current crop of low power light fittings inadequate? We have a set of downlighters in the house that I put replacement CFL lamps into and we've never been satisfied with their performance since – slow warm up and poorer light output being our two main beefs. I found recently on eBay a Hong Kong based company selling replacement LED lamps made with Surface Mounted Devices – the light emitting bits are on the outside, not behind a glass screen. The ones I found have 60 of these LEDs on one 2" diameter replacement lamp. Each unit cost only 99p (but cost £3.29 to ship from HK) I ordered six and they all arrived and work

well. The amazing thing was that they were each mailed separately in their own packaging – we had five arrive one day and the sixth about four days later. So if you have problems with dim downlighters there is a possible solution, but you'll have to use the internet to do it!!

On a lighter note – sorry about the pun – last September we went to Cyprus on holiday. We normally take a walker and book a hire electric scooter at the destination. To “fill the gaps” we book “Passenger Assist” throughout to ensure Carolyn had necessary help through the airports. On getting off the plane at Cyprus we were offered a wheelchair which was apparently a private one – it had a comfy rug/blanket attached. So we turned this away explaining it wasn't ours. We finally got into the airport building and got Carolyn seated in an airport wheelchair. What amused us was that during our queuing for airport security, customs and baggage reclaim we saw the same wheelchair being moved around the airport by different staff obviously “looking for its owner”. Carolyn was asked several more times “is it yours?”. Eventually we saw it again with the owner sitting in it just before we left. It just shows these items can have a life of their own!!

Now a request for information – we have had some members mentioning on the email list that they had used Whole Body Vibration (WBV) equipment. Basically this is a machine with a plate which you stand on and then it is made to vibrate at varying intensity and/or frequency. It has an overall effect in increasing muscular activity and circulation as the whole of the body responds to being vibrated. Some reports say that five minutes on such a machine is equivalent to a 30 minute work-out. Apparently the technology was developed by Russia during the Cold War space race as it was found to help in countering the effects of weightlessness experienced by cosmonauts. This equipment is now coming into some gyms as the benefits can also be useful to the ordinary person. I just want to know if any more HSP'ers had tried such equipment and what their experience had been of it.

Best wishes

Dave Harris

Fundraising & Skydive for HSP

Dear All,

I wanted to let you all know that I am currently organising a group skydive in order to help raise funds for the HSP charity. You may or may not already know that I did a bungee jump in October 2009 and raised over £1400 for the charity. This time I have decided to raise the bar higher and, instead of jumping from 170 foot, this time I have decided to jump 13000 foot! I am writing today to see if there are any members that are interested in joining me in the jump. I have already had interest from a few members and I hope that maybe a few more would like to try. I am organising it for Saturday 30th July 2011 at Beccles Heliport near Lowestoft.

If you are interested you can contact the jump crew at jump@ukparachuting.co.uk or you could visit their website at www.ukparachuting.co.uk. Even if you are not interested in jumping I would love it if you could come along and support those who are.

On a separate note I would like to say a huge thank you to my wife Louise and her workmates at Medacs and to Ginny Powell from the Hertford Round Table for raising £186.69 between them for the charity. Louise organised a cake sale and also persuaded people to donate money rather than send each other Christmas cards and Ginny arranged a Naffle – a raffle of all the naff Christmas presents that people got!

Ian Kitchen

Members' Letters

Dear Members

I've read a lot of interesting stories from HSP members in this newsletter about their cycling. So I thought I would tell you about my cycling. I started cycling at 7 years old and loved riding my bicycle. I would always ride it to school instead of using the bus, and I done my paper round on it. When I turned

13 years old I noticed there was something not right with my legs because I couldn't run anymore and could only jog.

I got diagnosed with hsp when I was 18 years old. As the years went by my legs gradually got worse and this resulted in me walking a lot slower and couldn't walk as far, but I could still go on far bike rides on my mountain bike doing many miles. However when I turned 21 years old I couldn't ride my mountain bike very far now because my legs were too stiff and even if I tried my hardest to carry on and ride my feet would slip off the pedals. When I turned 21 it was the beginning of the end of my manual cycling because this problem with my feet slipping off the pedals was frequent. So I could no longer ride a manual cycle. I've saw quite a lot of old people on electric bikes and this seemed like the perfect bike for me because if my legs got too stiff I could rely on the electric motor to do the pedalling for me. Well, I bought an electric bike in 2007 and it's been absolutely incredible transport for me because it gives me opportunities to get to and from places. Electric bikes works well for me so it might work well for the hsp members?

All the best,

Daniel Gibson

The full story...

Firstly my background. I am 57 and was diagnosed with a HSP Spastin anomaly 12 years ago. This has progressively worsened but I've yet to surrender to a wheelchair.

My tale starts on New Year 2007 when after a quiet Festive Season (over indulgence of alcohol and unusual diet is not wise) I was giving the kitchen a good clean up. As it progressed I became aware of some slight discomfort which I put down to overreaching due to not moving my feet enough. This worsened so I sat down and rested. It got a lot worse and became sharp spasms in my left chest especially when breathing. Called NHS Direct due to it being a holiday and Paramedics were sent. They, like me, suspected a heart attack but the ECG was clear. Thus the condition was put down to a HSP reaction to a muscle strain and Diazepam and Diclofenac Sodium were

prescribed and I felt that I wasted everyone's time.

Forward space to mid-September this year and I caught a real cough and cold, the type you only get once in ten years or so. For 12 days I had a continuous streaming nose, weeping eyes and lumpy chesty cough. This combined with my hearing problems in my left ear added to the balance problems intrinsic with HSP so after a couple of falls I had a quiet time mostly sitting at the PC. After it cleared up I set about clearing a flower bed of my precious giant lilies prior to some scheduled building work. Trying to take things steadily I spread the work out over several days but I was determined to get those somewhat deep bulbs out. Then I started to become uncomfortable. Had I strained something or got a bit of cold in my back? I finished the bit I was doing and went in to sit and rest. It got worse. The pain was all on my right side. The muscle between the shoulder blade and spine, the top of the shoulder all felt as though they were strained. This spread to just below my ribcage both at the front and back even when not moving. Decided it best to rub on some Ibuprofen and take some Dihydrocodiene and lie down. BIG mistake! I couldn't breathe at all. Screamed for help and got raised up and boy that hurt. I was hyper-ventilating but each short breath hurt like hell. 999 and paramedic arrives shortly before an ambulance. ECG was clear and some spray-on painkiller administered and I was lain down in ambulance (in hindsight not wise) and taken to A&E. The doctor there was puzzled and although knew nothing of HSP was trying to put it down to it. Thus I was admitted to the Neurological ward with painkillers and oxygen although the Consultant was adamant that it wasn't "his area". X-rays, Ultrasound and MRI scans located the cause, a Pulmonary Embolism and it wasn't the first..

PEs are a blood clot from the legs in the lung similar to DVTs which usually occur after a long period of activity like long haul flights. Statistics point to 10% mortality rate for PEs so I consider myself lucky. I met my Consultant a couple of weeks later and when asked if PEs were a greater risk to HSP

sufferers due our reduced leg activity replied "yes, but we can't put everyone on Warfarin just in case".

So the bottom line is if you get major chest pains call 999 immediately and if the resulting ECG is ok then make it clear that your condition makes you susceptible to PEs and that you must get urgent hospital treatment. It seems that PEs are not high on their possibilities list. This may need reiterating on arrival at A&E. They may take some persuading if they don't have the HSP awareness but mention its similarity with MS as this also has the same susceptibility. I don't recommend lying down in the ambulance.

My future. A lifetime on Warfarin with regular blood checks to ensure that it's thin enough to reduce recurrence but not too thin. Self awareness to monitor bodily functions to check for internal bleeding. (It is after all used as rat poison). A watch on my diet as many things affect the Warfarin, eg Cranberries, green vegetables, aspirin, Ibuprofen, Diclofenac. Having a handy supply of plasters because every little nick drips blood and I find myself getting more as I get clumsier. Changes to medication as I can't use Diclofenac but all the codeine based analgesics are inclined to cause constipation.

John Pepper Region 5

Dear All,

October's HSP Newslink impressed upon me the importance of how, in so many different ways, we confront HSP and still somehow get a kick out of life. Our neurological problem need not be a psychological one if we can limit the significance of the restrictions that it imposes on us. HSP may well affect everything south of the equator to a gradually worsening extent, but that leaves unaffected both arms that I am reliably assured are attached to us in much the same way as our legs. Using elbow crutches (since March 2009) in preference to a wheelchair that is awkward going up and down obstacles, I have found a much greater ease of movement by swinging myself bodily forward at a modest conventional walking pace. The triceps

muscles in the upper arms have, among others to be coaxed a bit, but, after a while, they suffice admirably. 'Use it or lose it' MUST never be forgotten, though, as the less we struggle to use our legs the more the paralysis takes over.

I was fitted with an intrathecal Baclofen pump in December 2007 and, while continuing with oral baclofen pills, have only this year reached what I think is the optimum rate (45.06µg/day). I was achieving a marginally greater ease of movement as the rate was increased, but then, quite unforeseen, the drug started adversely affecting the bowel and bladder muscles. I find control of the latter, even overnight, relatively minor to constipation. While trying to avoid the regular use of artificial laxatives but nevertheless overcome the malfunction of the muscles lining the large intestine that should naturally expel faeces, I find watery fruit (eg strawberries) provide the necessary 'irrigation'. Control of our diet is not to be taken lightly!

Like Christine Snow, I too genuinely sought and found God in all of this. As someone living on their own, independently without supportive relatives, I have found His presence in this psychological battle to generally maintain that all-essential positive outlook despite HSP, quite invaluable. Dull moments there will surely be, albeit forgetably brief if we can otherwise enjoy experience of such quality that the everlasting memory of it overwhelms that lingering tendency to feel oppressed.

Visiting unusual places can also stimulate a healthy desire to know more about them, so enlivening our grey matter that is so worthwhile, however demanding all this may seem at the outset. We are all surely the product of our lifetime's experience, so where and when we can let's make it a good one! Aware of this, Christian friends of mine invited me to join them on a trip to Egypt and Jordan, including a day in Petra which I had long thought was beyond my reach. That I have now stood with my crutches, temporarily unaccompanied, in

front of the Treasury 'building' and, on another occasion at the lowest place on earth, tested the supportive powers of the very salty Dead Sea will have forged memories forever available as a fillip when my determination seems inadequate. I'm no theologian, but I might be getting to understand A LITTLE MORE ABOUT 2 Corinthians 12v9; what an experience! To have physically struggled however slowly, but surely, to reach a desired objective is all the more rewarding for the likes of us and is surely an inspiration to breach another frontier, without undue stress, only when it feels right to do so. This confidence, that is needed spontaneously even when we don't know all that lies in store, I have found is God given. So I can only hope that my strong inclination not to be beaten never overwhelms His inspired judgement, for the choice is always mine.

John Moule Region 8

Hello one and all, I am currently suffering with a painful right thumb and thought it was wise to pass on the reason to you all.

I have diagnosed it as Repetitive Strain Injury (wonderful thing the internet) which is making my right thumb muscle ache, at times to the point of being useless with loss of grip.

I woke about a week ago from the pain and just thought it was a bit of cramp but it didn't improve much over the coming days. Getting on with life I was playing an addictive card game on my Blackberry phone and when the pain got worse alarm bells rang that this was the culprit.

On further investigation of the internet I found to my amazement a condition known as Blackberry Thumb. Yes! It's true, a condition caused by the Blackberry phone. Well it did make me smile, even with a sore thumb. This is not restricted to Blackberry but all of today's smart phones and the condition can be very serious, with some cases resulting in surgery! So be warned, use your fingers some of the time to help out the old thumb.

Best wishes to you all and thumbs up from me.
Peter Bateman Region 6

Regional News

The Regions 1 and 2 November meeting was a special occasion.

Our speaker, Amanda Edwards, a Neuro – physiotherapist, talked about FES (Functional Electronic Stimulation). Amanda definitely benefitted from ‘audience participation’ in that members, such as Michael Jarvis and Ian Bennett, were able to contribute and show how FES worked for them or, as in Ian’s case, some of the more recent developments.

We were also delighted to welcome a number of new members to HSP and not necessarily new to our regions. A big thank you must go to those members who will and regularly travel to the regional meetings outside their home areas. There is so much to be gained from the opportunity to share and meet members. The blend of new and more regular attendees seems to work well. We are very fortunate that members’, who joined us for the very first meeting, as new members in Meadow Court in December 2000, are still coming ten years on.

As hinted earlier in the text, the special occasion was celebrating ten years of the Region 1 and 2 Afternoon Teas. As a lovely surprise for me, Lorraine Saupé gave a speech about the ten years of our twice yearly meetings and then presented me with some lovely flowers, silver and purple balloons mentioning our 10 years and an envelope containing a very generous gift that I will enjoy spending. Ian Kitchen made a delicious chocolate cake which certainly did not last long!!

Although Lorraine’s speech was focused at my role, deep thanks and credit must go to Michael and my parents. Michael is always there supporting and helping me in every aspect of my life affected by HSP, including our meetings. Very sadly

my parents, who have supplied the tea for many of the meetings, could not attend. At the time of this 10th anniversary meeting both were terminally ill in hospital and since then both my Mum, known as Katie to many, and dad have died.

Sincere thanks to you all for your contributions to Regions 1 and 2 over the past ten years. We appreciate those members that used to attend and are now unable and those that continue to make the journey to Milford.

Jane Bennett

Forthcoming Events:

Region 4 get together

Saturday March 26th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Region 3 Meeting

June 4th 2011 Venue to be confirmed

Afternoon tea Regions 1 & 2

Saturday April 16th 3 – 6 pm
Milford Day centre
Contact Jane Bennett on: 020 8853 4089

Region 6 (Wales) Meeting

Saturday April 16th
Some members will arrive earlier for lunch -
All welcome
The Atlantic Hotel, Porthcawl
Call Peter Bateman on 01656 788502

HSP Support Group AGM

Saturday June 18th
Trident Technology and Business Centre
Leamington Spa
Full details will be despatched shortly

The Mobility Roadshow

East of England Showground
Peterborough
30th June, 1st and 2nd July
www.mobilityroadshow.co.uk

New Members

We welcome the following new members:

Alistair Fielden
County Durham
Region 10

Angela Wilson
Dronfield
Region 9

Brooke Wyatt
Surrey
Region 1

Brynley Sowden
Cardiff
Region 6

June Brooks
Norfolk
Region 5

Leanne Piccirillo
Winchester
Region 1

Michael Brooks
Norfolk
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.

Useful Contacts

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