



# HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 39 – September 2016

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

## 1<sup>st</sup> Potato Pants Festival a success



The ladies race at the Potato Pants Festival

On June 4<sup>th</sup> following many a sleepless night after months of planning, the first Potato Pants Festival was held in East Dorset.

It took place at a small community farm called High Mead Farm and all profits were to be split equally between the farm and HSP. The farm provides opportunities for people with learning and physical

disabilities, mental health issues and for disengaged youngsters.

We kicked off at 10am with the first of eight musical acts. There was at least a 30 minute interval between each musical performance and this time was used for people to get involved in the potato pants races. Several pairs of special trousers had previously been made that could

easily be worn on top of clothing. Ten kilograms of potatoes were inserted within these trousers and many people took part in races. The idea of this of course, was to give members of the public an idea of what it may be like to have early stage HSP. It was amazing how people loved taking part in this activity, which can be clearly seen by the expressions on faces in the photo on the front. The Wimborne town crier started all the races and continually reminded people why they were doing such a crazy activity.

There were various food stands and a bar that was supplied by Wimborne Brewing Co. The children were kept entertained by a bouncy castle, coconut shy, crockery smash, face painting, not to mention the various farm animals and wheelbarrow races. Terry Duffy had a stall selling his wood carvings and all proceeds went to HSP. We borrowed a golf buggy from a local golf course and this was available to anybody struggling with mobility. The music and merriment continued until 11pm. We were very lucky to have Rachel Stroud performing in the afternoon, Rachel was a contestant on The Voice and she got to the knock-out stage. The entertainment concluded with the excellent local band Black Water County.

A total of 350 people attended including several members of our Group.

An amazing profit of £2600 was made after settling all the bills for things like portaloos, generator hire and refreshments.



The amazing Rachel Stroud from ITV's 'The Voice'

Having now witnessed how much enjoyment people had, I believe that the Potato Pants racing could really take off and help make this

a much bigger annual event. The name 'Potato Pants' is certainly very memorable and many people have insisted that I don't change the name. Most of the feedback received has been very positive and plans are already in place for a similar but even better event next year. I've already been fortunate enough to have an amazing musician agree to perform next year at no expense to the Group. Roll on June 3<sup>rd</sup>.

## Chairman's Column

Those of you who attended this year's AGM will realise that at the very last minute I decided to serve one more year as Group Chairman. This will definitely be my final year and consequently the title of this column will change to: Editor's Column. I have to admit that I felt a little guilty when, during the AGM, I was presented with some gifts and cards which I believe were for my time as Chairman. I can't thank all involved enough for their generosity and very kind words. I notice that it's no secret that I enjoy the occasional beer.

While on the subject of the AGM, I'd like to thank Stephen Connor for taking such amazing photos. I particularly like the one below which we now use as the main picture on our Facebook group.



Our Facebook site, Hereditary Spastic Paraplegia's Unite, continues to be very well used and now has over 1000 members. I'd never have expected this when I created it several years ago. Thank you to everyone who makes such good use of it.

Fundraising for HSP is going well with many people recently taking on incredibly challenging activities. I'd like to highlight a

few individuals but of course everybody's efforts are greatly appreciated. Beginning on May 21<sup>st</sup>, Stuart Montrose walked from Lands End to John O'Groats and finished on June 23<sup>rd</sup>. At a similar time, our very own committee member, Simon Hubbard, took on the same challenge but on a bicycle. A friend of mine called Graham Moody is currently in the middle of completing five gruelling runs for us. Three of them are full marathons and the other two are even longer. He's recently completed a 37 mile run in Salisbury in the blazing sunshine and he proudly wears the HSP running shirt at every event. Graham's employer is doubling the money he raises.



Graham Moody finishing the New Forest marathon

Many of you who are on Facebook will have noticed that my daughter Jade is also fundraising for HSP. She is training hard and has now done two half marathons and is doing the Bournemouth marathon in October.



Jade completing the New Forest Half Marathon, proudly wearing her HSP running vest

Both Jade and Graham have fundraising pages on JustGiving.

I'd also like to thank Terry Duffy who as many of you know is a very skilled wood carver. He sells much of his work at HSP events and gives all the proceeds to HSP. Terry had a stall at our AGM and is planning something similar at the Ashburton meeting in October.

Peter Bateman continues to raise an astonishing amount of money for us with his key ring and pen sales at various locations near his home in Porthcawl.

Fundraising is particularly important at the moment because the Group has recently agreed to fund some research at Exeter University and this will be our largest funding commitment to date. We have agreed to provide £10,000 at the beginning of the next three academic years and this funding will be matched by both the university and the university's Diamond Jubilee Scholarship Fund scheme, totaling £91,000. This will fund a PhD student working with Professor Andrew Crosby and the research he is doing in HSP. The PhD studentship will be named; *The Hereditary Spastic Paraplegia Support Group PhD Studentship*. To put it simply, without our funding, the PhD studentship wouldn't happen.

Immediately after the Chairman's Column is a copy of a letter from Exeter University, thanking us for the important funding.

I am very proud that we are now able to contribute to research in such a significant way, but we must focus on fundraising activities to enable us to continue such support.

I've recently been to The National Hospital in London for my annual appointment and on this occasion, thanks to my wheelchair, it was a particularly interesting experience. On account of mobility issues I gave up using the London Underground about three years ago as it had become too much of a struggle. For this reason, for last year's appointment I'd decided to use taxis to get me from Victoria Coach station to the National hospital and back again following my consultation and the taxi fares had totaled £45. This year, I thought I'd try and save some money so I

downloaded some good maps with the intention of self-propelling in my wheelchair to and from the hospital. It was a lovely day and the route took me past Buckingham Palace, down The Mall and through Trafalgar Square. It was a very enjoyable experience, as indeed was the trip back to Victoria. What made it even more satisfying was the fact that the £45 remained in my pocket.

The reason I'm discussing this is because on a couple of occasions recently, people have expressed sympathy when I tell them I use a wheelchair. They obviously don't realise that I'm very happy to use my chair and the fact that it gives me so much freedom is a big bonus. To me, a wheelchair certainly isn't a negative object. Recently, I was even using it on the dance floor, but the beer may have been a contributory factor. I feel the same way about my mobility scooter. I do miles and miles on it locally and it gives me so much freedom.

Many thanks to all who've contributed to this newsletter. Please keep your articles coming in to share any interesting news or information with other members. Anything that's really exciting is likely to go on the front cover so please also send relevant images.

Following Flexyfoot's attendance at this year's AGM, Georgie Powell, their Operations Manager, has kindly offered our members a 10% discount on all their products. Simply

quote HSP10 when ordering. Please see Georgie Powell's article on page 6.

As always I look forward to meeting up with many of you at forthcoming meetings and events. I'll almost certainly be at Ashburton on October 15<sup>th</sup> but it does clash with a Bournemouth match.

**Ian Bennett**



**Dear Ian**

On behalf of the University of Exeter and Professor Andrew Crosby, I am writing to thank the Hereditary Spastic Paraplegia Support Group for its gift of £30,000 (as detailed in the Diamond Jubilee Studentship Gift Agreement of 11/08/2016). Your generous support for the PhD in "Investigation of novel molecular pathways underlying motor neurone degenerative disease" will be a wonderful contribution to research.

We will be in touch as the project develops and would be delighted to welcome you to Exeter sometime soon.

With very many thanks

**Kristen Gallagher**  
on behalf of Exeter University



## Adam's Column

Firstly, I am pleased to announce the launch of my 2016 on-line survey for people with HSP. My main focus for this survey is understanding fatigue, which many with HSP suffer from. I have selected 3 different short-form fatigue questionnaires, and I will be interested to see which people prefer. I also ask questions on bladder and bowel issues. Bladder issues are well known, but whilst bowel issues are reported less frequently there still seem to be many who have them. Finally, I ask about how people find out information about HSP.

Following the previous pattern, I will collect results until early 2017, then analysing these in time to publish the results on my blog on rare disease day, 28th Feb 2017. This year, I am also collecting e-mail addresses to build up a list of people interested in taking part in these surveys in future years.

I welcome anyone with HSP to complete the survey:

<http://hspjourney.blogspot.co.uk/2016/09/autumnal-survey-2016.html>

The rest of my column gives a summary of my visit to the International Meeting on Spastic Paraparesis and Ataxias organised by the Spatax network and the Ataxia Study Group. The meeting

was held over 3 days. I have gone into more detail on my blog than I have in this column, so readers are welcome to go and see more there:

<http://hspjourney.blogspot.co.uk/2016/06/international-meeting-on-spastic.html>

The meeting was at the same time as the AGM, which explains why I wasn't there. Thanks are due to the HSP support group for covering my expenses.

The meeting was really friendly, and I felt quite at home there. The network of researchers feels really close knit, and I was pleased to see and hear about people chatting with each other and sharing their knowledge and findings. In many respect the coffee breaks, lunches and evening social events are just as important as the presentations as they allow people to go and share ideas.

I spent some time talking with the people from Euro HSP who are keen for the UK group to join. This is quite the opposite to the EU referendum held in the UK on the first day of the meeting (and reported in the second day) which resulted in the beginning of the UK's EU exit. I also think that the various patient groups need to work together, and not just the HSP groups, but those groups for people with similar conditions - Ataxia, CMT, ALS and others.

This column just reports my key take-home thoughts from the conference. You can read further details on who said what on my blog.

The knowledge of HSP increases. The day-to-day variation in symptoms for an individual can be significantly greater than the year-to-year progression of HSP.

One group identified potential biomarkers for HSP which correlate well with disease severity, and another group report the progression of changes in gait with progression of HSP. There were several papers looking at how the different types of HSP have different ages of onset, different levels of severity and different symptoms. The genetic mutations for HSP can vary in size, and potentially affect more than one gene, with potentially more than one consequence.

Several researchers talked about genetic testing, with some noting that test results can be ambiguous. Whilst the number of genetic tests for HSP grows they still only cover about 20% of cases, leaving some 80% without a clear diagnosis. Another issue is that such a test can show "incidental" findings - i.e. a gene is matched which was not part of the original search remit - consent is needed from the patient to find and report these findings.

Researchers are looking for bigger/better patient registries. There are genetic and clinical overlaps between Ataxia, HSP and ALS, as well as other conditions, with symptoms and the way they feature being common between conditions. Working together and sharing data helps. Some are calling for the usual 'pure'/'complex' classification of HSP to be revised. Overall, some 5-10% of rare disease patients have two different conditions. Changes in health can be indicators of underlying problems, for example a chronic cough.

In terms of new treatments, one study reported the use of Simvastin for one patient with SPG5A. This reduced a specific type of cholesterol encoded by the affected gene.

Treatments are more effective the earlier they are given. Various drugs and therapies were mentioned, but the overall message was that if these are given after the symptoms are severe there is less chance of recovery, particularly if the nerve cells have died. Some researchers are looking at repurposing existing drugs for HSP.

Several groups reported balance training, gait training and the use of wearable "stabilisers" for patients with Ataxia. I don't know if such approaches would also work for HSP. It's an avenue for someone to research. It was said that the gait training was found by the participants to be difficult to do, but showed good results. This ties in with the "use it or lose it" slogan.

Several researchers use and talked about animal models of HSP. Whilst I accept that this could be considered controversial; these models do greatly help the understanding of diseases.

**Adam Lawrence**



It was with great pleasure that I accepted the invitation to come along to the recent HSP AGM as I had been unable to attend in 2015. I was looking forward to sharing our products in the hope that they would go some way to improving mobility and access for stick and crutch users within the group.

I was very excited as I pulled up at the venue and I energetically started to unpack my car and start setting up, but then a very strange thing happened. I was beginning to feel that I may be in the wrong place. The reason being, as I was quietly preparing to unveil the benefits of Flexyfoot, the more and more people I passed that were already using Flexyfoot on their crutches and sticks. The more I looked, the more it seemed to be a Flexyfoot Users AGM! I felt that there was very little I could offer to enlighten or convince the group as to the benefits of our products.

That being said, I was received warmly and during my presentation there seemed to be genuine interest not only in the products but in the company and our efforts to continually improve.

It was lovely to be able to talk about our new products that are launching as we speak. To those familiar with our products you will know that we started only a few years ago with a simple replacement ferrule designed to fit to almost any walking aid, that would increase grip and stability and reduce upper body pain. This product provided up to 50% more grip than a standard rubber ferrule/tip, lasted much longer and made walking more comfortable.

Since then we have developed our own range of walking aids; sticks, crutches and poles, based around our own unique oval handle, all designed to improve the user experience.

At the AGM I was proud to be able to reveal our latest development – a new type of “foot” for our ferrules. The new foot is made from a

new material and has a new tread pattern and has been designed specifically to improve grip and stability on some of the trickiest surfaces of all – wet or shiny floors. The new tread has been tested and has been shown to provide up to 250% more grip than our original design.

With testers taking the new foot into and around pools, saunas, steam rooms, waterfalls, sports halls and golf courses, they have had real world testing and proved their stuff. I am pleased to say these are now available and are interchangeable with existing ferrules. All HSP Newsletter readers can get a 10% discount on our products by using the code HSP10 either on our website [www.flexyfoot.com](http://www.flexyfoot.com) or with our Call Centre 0800 0285888.

**Georgie Powell**  
Flexyfoot Operations Manager

## HSP Group Grants

**Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier.** The maximum grant available has recently been raised. Completion of one year’s membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

## Collect Stamps! Raise Funds for HSP!

For a long time, Phil Burton has been quietly raising money for the HSP Group by selling used stamps.

They have been collected by members in Regions 1,2 and 4 and taken to the Region 1 and 2 meetings for Phil to pick up. Phil wants to thank all those people for their support. He sends the stamps to a local stamp auction company which sells them on to collectors.

In order to send a batch off, Phil needs a dustbin liner full of stamps – which is a lot of stamps! So he needs our help too.

**So, please, would everyone help by collecting their own stamps and by asking their friends, family, work colleagues and maybe, even, local businesses to collect stamps for HSP.**

It is a very quick, easy and painless way for us to help.

Phil can only use good quality, British and Foreign stamps, not the boring printed labels they use so much these days! He needs “good” stamps, so, not defaced. They should be trimmed so that there is about ½ inch (1cm) of paper around them. This protects the edges but if there is too much paper the company will pay less per kilo for the whole batch.

If we can all keep an envelope in the kitchen and trim and put our stamps into it as we open the post Phil will be able to raise even more money for HSP.

If you want to post them then put them between thin card, sellotaping the edges because they can move around in the package so that it won't go through the slot and poor Phil ends up paying a surcharge.

The idea is to use our growing network of branch meetings and the AGM as collecting points, if the leaders of meetings are willing. Then anyone going to the AGM or a Region 1 and 2 meeting can take the stamps on the next stage of their journey to Phil. Anyone who can't get to a meeting could pass them onto someone who can and local coordinators might be able to put people in touch for this.

If you want to post the stamps, then do so. They can be sent to Phil Burton at 17, Strathmore Road, Worthing, West Sussex, BN13 1PJ. Do, please, check the postage carefully, for Phil's sake.

Hopefully, we can all collect stamps for HSP and help Phil to support the Group that supports us.

Every little helps! As Phil's employer says!!

## Members' Letters

**Dear all,**

I write again of my sole adventures, armed only with elbow crutches and a reliable car with hand-controls, that do seem to suggest

that HSP does not, at least in my experience, through any conceivable influence on my psychological state, adversely affect my quality of life.

Rather than scaling the heights of well known St. Paul's Cathedral as in 2015, this year the calling came from a far less well known rocky outcrop called 'Muckle Flugga', that is just within the northern extremity of our British Isles. As it turned out, with HSP I got within two miles of it but not within sight of it; able bodied folk were getting a mile closer, within sight of both it and some spectacular cliffs. Never mind. Nor did I reach a virtually unique ancient rock formation of volcanic origin known as the Grind of Navir in the western part of northern mainland Shetland. It seems I may well thrive on the unusual but, in this case, not casually getting lost! Conceding defeat goes crucially with realizing one's limits, particularly when you're on your own with few passers-by.

While that may have been the turning point of my home made trip, involving nine ferries to Unst, the northern most inhabited Shetland Isle, all was certainly not lost as there was a good deal else to see on my planned round trip. To mention but a few. In the Orkney archipelago lie five islands that had to be joined in World War II by the 'Churchill Barriers' to block German U Boat access to the Royal Navy anchorage in the sheltered Scapa Flow. On one of these islands, Lamb Holm, lies the Italian prisoner of war chapel which they may have used for only a short time before their release in September 1944, but to this day remains a supreme example of what can be achieved in terms of its inspired internal decoration from very rudimentary resources. Two days later, on Unst, which over a thousand years ago would have been the first landfall of the adventurous Vikings in their incredible conquest of the elements ultimately to reach Vinland (today's America) long before Columbus, there are side by side unenclosed reconstructions of one of their longboats and long-houses. It is truly remarkable what they achieved so long ago with so little of what we take for granted today. I further looked in two museums, one concentrating on textiles and the other on the

'Shetland Bus', that is the extremely hazardous crossings of the North Sea made in small boats to aid the war effort in German occupied Norway. Our wonderful weather behaved itself on all but a day or two.

The sense of fulfillment I gain from these jaunts is immeasurable and inspires me to 'reach out' again. That just may be Iceland, where I first went in 2007 'on one stick'; this time, I must have a well acquainted companion (in the interest of mutual understanding) to drive the hired vehicle into the extraordinary volcanic/glacial interior. More anon. In the wake of challenges met and very carefully and gradually overcome, ambition like this is truly wonderful as it fires all the essential planning and is surely conducive to a healthy state of mind, tethered, as I've always said before, only by our caring heavenly Abba Father. As in St. Paul's, there certainly were times when I sensed I was pushing my limit, but never thankfully, to recklessly exceed it. A confidence founded on this spontaneous inspired judgement is indeed another fine thing.

**John Moule Region 8**

**Dear all,**

The Offa's Dyke path is the ancient border between England and Wales, running from Prestatyn to Chepstow. After reading in the May edition of the Newslink that Derek Weeks (Kay Freeman's son) was going to walk the Dyke for HSP and as I live on the Montgomery part of the Dyke, I got in touch with Derek with the offer to help with a bed and a meal.

On a Monday evening I received a phone call from Derek who was in Buttington where he had pitched his tent for the night and was in the Green Dragon pub, so I drove up to meet him.

After much chatter about Offa's Dyke and his journey so far and his mum's HSP and my HSP and our families, we decided I would take Derek's rucksack in my car to save him from carrying it as I had planned to meet him the following day at Blue Bell Crossroads. After receiving a phone call from Derek midafternoon the next day, confirming he had

arrived at the Blue Bell Pub and was having a coffee with the landlady who is a friend of mine, I went to meet him. After picking up Derek, we drove back to the Green Dragon to pick up his tent and sleeping bag. We then went for a drive around Welshpool to see Powis Castle and on to Montgomery Castle, but it was a grey day and Derek had already woken up to a covering of snow so we made our way back to Churchstoke for a meal. After his meal, Derek went for a well-earned pint in our local pubs.

Wednesday morning, I returned Derek to the Blue Bell Crossroads to continue his walk into Knighton and I agreed to take his rucksack again and meet him later in Knighton. That afternoon I drove to the Offa's Dyke Centre in Knighton to wait for Derek's arrival. It was good to see him coming over the brow and into the Centre, aching but pleased to have completed another section of the Dyke. After several coffees and much chatter I left Derek to find his way around Knighton in the afternoon sunshine.

**Carol Gittins Region 6**

**Hello, my name is Chris Jones** - I joined the Support Group in April. I am 74 years old. I met some of you at the AGM in Leamington Spa. What a coincidence, it was almost opposite my local Rehab Hospital! At last I meet other people with HSP!!

As a toddler the back of my left leg was stiff. I walked strangely and PE was a nightmare at school.

In my 50's my hollow back ached if I stood around a lot. I decided to try yoga. This helped enormously and I began to do stretching exercises at home. Over the years I picked up lots of different exercises from various sources, in order to keep my back stretched out and later on my legs. Also I never found physiotherapists any help at all. They did not seem to understand that I had difficulty with balance.

At about 55, I started to trip and stumble, and fall over. A podiatrist helped me with an orthotic, which I put in my left shoe. He said I had one leg shorter than the other. (I am now ½ in lame and have built-up shoes made by



courtesy of my local cobbler). I am described as having a spastic gait.

At 60 my legs started to ache in the evenings and often woke me in the night. I used cocodomol but it was not very successful. A neurologist diagnosed Restless Legs Syndrome at 65. Then I read a letter in a magazine stating that Ropinerole (a Parkinson medication) had cured his RLS. I am still using this kind of medication, but changed to Sinemet and Pramipexole a few years ago. I also take extra iron and magnesium supplements. Still not sure if I have RLS!!

At 69 I was diagnosed with probable HSP, and various other specialists' appointments followed. I am now being tested genetically at the Radcliffe Hospital, but HSP is still to be confirmed.

I loved folk dancing from my early 20's. I stopped 30 months ago at 72 as I was a danger to others as well as myself. It was the worst time in my life when I had to give it up.

I then got a Blue Badge and a 3 wheeler, followed soon after, by a 4 wheeler in order to walk safely. This stopped me falling over!! Only occasionally have I used an electric buggy, and then only in the big modern precincts. My problem is that I cannot walk unaided around shops.

I joined the gym at the local leisure centre, over 20 years ago and go twice a week for 2 hour sessions. It helps with flexibility but does not halt the insidious and rather rapid progress of HSP. I am really struggling to walk now and do not enjoy doing so.

Stretching exercises have been my main weapon, together with RLS medication for aching legs. My 4 wheeler still enables me to walk short distances and to paddle in the sea, and my automatic car gives me a lot of freedom. My lovely husband Mike helps me quite a lot, which gives me time to still be able to go out on my own and maintain some independence. I even enjoy pushing a trolley around the shops.

My next appointment is for FES suitability at one of the Salisbury Clinics this August as a private patient. An NHS appointment would have meant a 10 month wait and I was

worried I may not be able to walk at all if I had to wait that long.

*Christine Jones Region 7*

## **My Little Trolley**

He's just a little trolley but what a help he is to me.

In the morning I have him to help me to get out of bed. Then the cereals and tea and mobile phone are placed on top. During the morning I'll take the washing out of the machine and place it on top. I have a rotary clothes line so I'm able to get up close to put all items on the line. Then, before going indoors, I collect my bucket, spade and scissors and all goes on top of the trolley. I always have plenty of dead heading to do as well as hidden weeds. Top layer comes in handy again – straight to the brown bin to get rid of the horrors. After washing the top, I make a cuppa, rest it on top and decide what to have for dinner. I can sit down with the trolley in front of me and prepare the vegetables.

Late afternoon I sometimes have a visit from my little three-year-old granddaughters. They love to have a little ride on the trolley – one at a time – around my garden with me pushing it. I'm then near to them for lots of kisses.

*Barbara Jones*

## **Regional News**

### **Region three social meet**

#### **September 2016.**

##### **Hello all**

After the Region three HSP meet in May 2016, I thought it would be nice to have a 'random' Very relaxed social meet in September 2016. It wasn't in the Newslink in June, because it wasn't an 'official' Region three meeting.

I posted the information on the Facebook 'Hereditary Spastic Paraplegia's Unite' site and also the HSP support group E-mail site.

I said that Roger (Hubby) and I would be at The Orange tree Pub, in Hitchin on Saturday 10th September at 13.30 and that if anyone wanted to join us for a late lunch, early

dinner, that would be lovely and to let me know, so I could give the pub expected numbers etc.

There were 12 of us that came along. Was lovely seeing faces I'd not seen for quite a long time. Maurice Charge came along with Lorraine and his Neurophysiotherapist, Sita Taylor, who joined us for lunch and chatted to anyone interested in learning more about physiotherapy for those with Neurological disease/conditions. Sita has said that she would be happy to come along to future meetings to do the same, if required.

Also, Maurice brought along some leaflets, regarding 'The British Wheelchair Association'. [www.bwaa.co.uk](http://www.bwaa.co.uk)

to pass on to members. I have a few, which I will bring along to any HSP meets, we attend.

It was voiced that some members would like to meet up at regular intervals in the future, as it helps get us 'out' which I am happy to do, as I always get a 'boost' from meeting up and chatting with fellow HSP'rs.

We all joined in conversations and made some plans. I will give more information after we meet up again in January 2017.

Our next region three meeting will be on Saturday 21st January 2017 @ The Orange Tree pub in Hitchin @ 13.30.

If you would like to attend this meeting, please let me know, so I can let the pub know numbers.

***Della Brookman. Region 3.***

## Region 5 meeting

Group 5 met on Saturday 16<sup>th</sup> July at the new meeting place – Chapel Court, Meadow way, NR6 5NU. We had two new members and Rekha Srinivasan, the Norfolk and Norwich Hospital Physio was with us again. We had good facilities for making teas and coffees and shared our problems with Rekha who gave us advice.

All enjoyed meeting and chatting and we hope more members will come to the next meeting on Saturday 15<sup>th</sup> October at Chapel Court.

***Barbara Jones***

## Forthcoming Events

### Afternoon tea Regions 1 & 2

Sunday November 20<sup>th</sup> 3pm – 6pm  
The Clockhouse Milford, GU8 5EZ  
Call Jane Bennett on: 020 8853 4089

### Region 3 Meeting

Jan 21st 2017 1.30pm – 4pm  
The Orange Tree Public House  
100 Stevenage Rd, Hitchin, SG4 9DR  
Contact Della Brookman: 07710 637 941

### Region 4 get together

Saturday October 15<sup>th</sup> 2pm onwards  
The Dartmoor Lodge Hotel, Ashburton  
Call Ian Bennett on: 01202 849 391

### Norwich Meeting

Saturday October 15<sup>th</sup> 2pm  
Meadow Way Chapel NR6 5NU  
Call Barbara Jones on: 01603 423 267

### Colchester Meeting

Sunday, October 9<sup>th</sup> 3 - 5pm  
Feering Community Centre  
Feering, Essex, CO5 9QB  
Call Hilary Croydon: 01284 728 242

### Region 9 Meeting

Saturday 15<sup>th</sup> October, 2 - 5pm  
Mickle Head Beefeater  
Eurolink, St Helens, WA9 4YR  
Call Irena Pritchard on: 01524 261 076

### Region 7 Meeting Birmingham

Saturday 15<sup>th</sup> October, from 12 - 3pm  
The Kenrick Centre, Mill Farm Road,  
Harborne, Birmingham, B17 0QX  
Contact Penny Cohen: 07818 288 738  
Email: pennycohen57@hotmail.com

### Potato Pants Music Festival

Saturday 3<sup>rd</sup> June 2017 from 3pm - 11pm  
£5 entry – pay on arrival  
High Mead Farm  
Ham Lane  
Ferndown  
BH22 9DR

## New Members

We welcome the following new members:

Amanda Snuggs Honiton Region 4	Jacqueline Russell Ashford Region 1	Patricia Pockett Hampshire Region 1
Andrew Ashbridge Falmouth Region 4	Jane England Carmarthenshire Region 6	Peter Hicks Emsworth Region 1
Carol Goodwin Coventry Region 7	John Andrews Gwynedd Region 6	Robert Jenkins Stratford on Avon Region 7
Christine Jones Leamington Spa Region 7	John McCullagh Rochdale Region 9	Violet Seggie Dover Region 1
Claire Davey Basingstoke Region 1	Kim Simkin Chipping Norton Region 3	Heather McRobb Dreghorn (Scotland) Region 11
Debbie Goldfinch Sittingbourne Region 1	Marjorie Conley Dawlish Region 4	Thom Penman Sunderland Region 10
Debra Malyan Newquay Region 4	Natasha Ewart-Jones Fleet Region 1	John Brombley Southampton Region 1

If you are interested in contacting any of the above new members, please contact the relevant area coordinator, or the membership secretary.

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## HSP Annual General Meeting 25<sup>th</sup> June 2016 Minutes

1. APOLOGIES FOR ABSENCE were received from Simon Hubbard, Adam Lawrence, John and Carole Moore, Mike & Ann Horsman, Hugh & Mary Beavan, Phil Burton and Lynne Hamblin.
2. The Minutes of the 2015 AGM were agreed to be a true record: proposed for acceptance by Caroline Begg and John Williams. They were approved by a show of hands.
3. COMMITTEE REPORTS:
  - a) John Mason presented the groups accounts for the year. Copies of the summary had been handed around to all attendees. John first gave thanks thanks to Sonya Mason for her assistance through the year and to Theo White as Auditor. After an opportunity for questions, adoption was proposed by Roy Myers and seconded by Della Brookman. This was approved by the meeting with a show of hands.

- b) Stephanie Flower welcomed new members to the meeting and hoped to be able to talk with them before the day's end. The Help Line had been very busy this year with a wide variety of calls for different subjects. Many people had been affected by problems with hospitals and with getting a clear diagnosis. On a personal note Stephanie reported that she had now had surgery on her spinal cord to implant a stimulator device for management of chronic pain - this is working very well for her.
- c) Dave Harris reserved the right to speak later if he spotted any omissions,
- d) Ian Bennett summarised the past year:
- **Local Meetings:** Although this had been a long process, he was delighted to report that there were now well established, regular meetings in the North West, and in Birmingham, Colchester, Norwich, Hitchin and both Region 1 (Milford) and Region 4 (Ashburton).
  - **Grants to Members:** The Group were still providing grants to members. A total of four applications have been received during the financial year.  
(NB Committee have agreed to raise the member grant limit to £750.)
  - **Research:** In addition, during this year the group had supported four research projects: Cahir O'Kane at Cambridge (Fruit Flies), Prof Henry Houlden at The National Hospital for Neurology, , Dr Andrew Grierson, Sheffield University (Mice), Prof John Marsden at Plymouth University.
  - **New Logo:** HSP World wide had adopted a new logo which we would hope to have on our web site soon.
  - **Fundraising:** a lot was going on - a short summary follows:
    - **Peter Bateman** was still selling HSP key rings and pens - he had now raised over £10,000 for the group. [Applause]
    - **Simon Hubbard** was near the end of his effort to cycle from Lands End to John O'Groats.
    - The **Old Thatch** pub and nearby Garden Centre continued with their all-year-round HSP focused fundraising.
    - A dress-down day at some offices had raised just over £140.
    - **Graham Moody** was running four marathons in aid of HSP. Ian showed a photo HSP running shirts we can provide for such events.
    - An old friend **Stuart Montrose** has added HSP to the group of charities which he was fundraising for by walking from Lands End to John O'Groats.
    - **Potato Pants Festival:** Ian briefly explained the term "Potato Pants" which had originally come from a remark by an American lady living in Austria trying to explain how HSP affected her "as though I had 10 Kg of potatoes in my pants". This has been adopted as a publicity slogan world-wide. Ian had used it as the theme for a music festival he had helped to organise in a venue near where he lives. It had been arranged with minimal cost to the group, and had been successful, with eight bands and over 300 people attending in the first year. Potato Pants races were organised in between bands. He expects to be running it again next year.
  - **Membership:** The group in the UK continues to gain about 40 members each year and about 20 are lost as people's circumstances change or they decide they have enough information. We also have 71 honorary members, mainly individuals in the medical professions who have expressed some interest in our condition.
  - **HSP Unite,** the Facebook Group for HSPers goes from strength to strength, having over 950 members. This is an international group, which is managed and moderated by our members. People have to request to join it - it is not open to browsing.
  - **Newslink:** Ian requested newsletter articles from members - it was mainly due to member contributions that we are able to publish it regularly.

- **Committee Membership:** We are always happy to have members volunteer to take on committee work - the more we have the more we can do. It is new blood and new ideas that keep an organisation relevant and dynamic - please consider if you can do it.
  - **Old/Unused Equipment:** Various items had been brought in - there may be something that you might find useful.
4. Election of Officers:
- Chairman, Ian Bennett** was proposed by John Flower and seconded by Hilary Croydon.  
**Treasurer, John Mason** was proposed by John Flower and seconded by Mark Tomlinson.  
**Secretary, Dave Harris** was proposed by Pat Reed and seconded by Penny Cohen.  
**Committee Member Simon Hubbard** was proposed by Lorraine Saupé and seconded by Hilary Croydon.  
**Helpline, Stephanie Flower** was proposed by Debbie Best and seconded by Della Brookman.  
**Committee Member John Moore** was proposed by Hilary Croydon and seconded by Richard Williams.  
**Committee Member Adam Lawrence** was proposed by Caroline Begg and seconded by Della Brookman.  
 All the above appointments were approved by the meeting.
5. Any Other Business. No items were raised.

#### Speakers:

The AGM was followed by talks from four speakers:

- Georgie Powell from ferrule company Flexyfoot.
- Debra Gordon and Lauren Moore, from continence products company Coloplast.
- Dr Paul Taylor from Odstock Medical (FES) Salisbury
- Amber Meikle-Janney, who described her experiences as a disabled skier.

## Notes on AGM Speakers.

### Flexyfoot

Georgie Powell represented this small company and its innovative products.

The main product is a no-slip ferrule for both sticks and crutches. It is a modern design with an easily (and inexpensively) replaceable "foot" which clicks into place. This foot anchors into the ferrule base which remains tightly fixed to the stick or crutch. This approach allows easy replacement of a worn foot. The company also produce and sell several ranges of sticks in both traditional and modern styles.

Fully researched, designed and now approved by all the relevant certification bodies, Flexyfoot has a strong following in countries around the world. The current UK Health Service is a fragmented place to sell into and each health authority needs to be "sold to" individually. This cost too much time to be worthwhile - thus the company has concentrated its UK sales efforts towards the larger commercial outlets e.g. Boots. Such chains sell the products well, as do many independent mobility stores. The range of products is steadily increasing (more sizes and colours, differing stiffnesses).

Plans are afoot to recruit staff in the larger foreign markets to promote/facilitate sales.

### Coloplast

Debra Gordon and Lauren Moore represented Coloplast and updated us on some of the products they provide to help with the continence issues that affect many people with HSP. They began by informing us that it was currently World Continence week.

They discussed catheters and catheterisation and surprised many present by how small their latest catheters are for females. The male catheter has to be a certain length in order to work properly.

They discussed male incontinence and how it can be managed by using a convey which is a clever system where a sheath is worn and urine flows down a tube which is attached to the sheath and fills up a bag which is usually worn on the lower leg. This system was demonstrated using their dummy who I believe is named Boris.

They also discussed their bowel irrigation system called Peristeen. This equipment allows the user to fill the bowel with water and after a short period of time, the bowel naturally empties itself and can consequently prevent much discomfort.

Further information on what Coloplast can offer can be found on their website:

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

## **Odstock Medical**

Dr Paul Taylor provided an update on the present status of the Odstock FES systems.

The devices provide electrical stimulus to nerves. The nerves then activate muscles. In HSP the most common use is to activate the muscles which raise the foot during walking, thus preventing the foot from "dragging". To achieve this, two pads are attached to the lower leg, and a switch is placed below a heel within a shoe. Once correctly placed, these can be used together with a control unit to supply pulses which activate the muscles.

Smaller and lighter devices were now in use, some of which clip to the leg and contain the pads - this makes the time to set up each day less. The foot switched can now link to the control box wirelessly, which also makes the system easier to use and less obtrusive.

Enough HSP users had now been supplied with the equipment that some measurements were possible showing the effectiveness of the device for HSP specific use. As a general rule it seems that use of FES improved walking speed over a measured distance by about 10%. There was also a corresponding reduction in effort as measured by heart rate.

Some of the patients who get benefit from the device are not able to perform the daily set-up routine themselves due to other physical or mental conditions. A surgical procedure has been developed to implant the electrodes along the relevant nerve. This removes the need to position the pads correctly each day. For these users the devices produce similar benefits to the normal equipment. The cost of the procedure and its invasive nature makes it only appropriate for a small group of individuals.

## **Amber Meikle-Janney and skiing - "HSP can't stop me!"**

Amber is now 17 and gave us a video presentation of the ways in which HSP has affected her and how she was developing her skiing skills despite the condition. Although there had been some indications of onset when she was younger, she had been able to develop a love of skiing on holidays. We were shown some short videos of her aged 6 on skis.

Since the condition started to affect her more, she started to look for ways in which she could continue to ski. She found information on-line about the charity Disability Snowsport UK and got in touch. They have helped her to learn how to ski in a seated position on a mono-ski. Time for more videos, this time of Amber as she was learning - lots of footage of crashes, eventually leading to some long runs!!

Amber, with some help from her Mum, then demonstrated her mono-ski by transferring onto it and showing how she can use it to get onto a ski-lift. This is something not for the faint-hearted!