



HSP Newslink

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

Issue 27 – September 2012

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

I conquered the London Marathon for HSP



Sophie Pritchard ready to run!

My journey to the finish line started back in November 2011 when I discovered I had been allocated a place in the 2012 Virgin London Marathon. Having run the race the year before, I knew a little about what was in store!!!!

My training started just after Christmas and for the next 16 weeks, I spent my weekends and evenings pounding the streets running (albeit some weeks harder than others!). They say that in running a marathon..... The real marathon is in the training, and the race itself is actually the reward! As odd as it sounds, it's definitely true.

I decided to make my training efforts worthwhile and raise money for charity - I chose the HSP Support Group as my mum suffers from HSP and I know what great work the charity does to support those affected by HSP.

So far I've raised over £700 and my employer will match my fundraising, which will total over £1500 including gift aid! If you would like me to help raise even more money, please visit my fundraising page at

<http://www.justgiving.com/Sophie-Pritchard0>

With my training in the bag, when race day came, I felt confident, excited and ready to race! Despite it being "the rainiest April on record!", Sunday 22nd April in London was a beautiful sunny and cool morning - Perfect for running! I made my way to the start line of the 32nd London Marathon along with the 37,500 other runners.

I thought I'd share my key race facts, highlights and lowlights with you!

My race fact file

I finished 26,802 out of 37,500

I was the 7999th woman to finish

I finished ahead of 40% of the race field

My average speed was 5.2 mph

My race high-lights

Seeing the smiley faces of my mum, dad and partner Rob waving and cheering at mile 15 and 19 (I definitely needed them by then!)

Knowing that every step I took was raising money for such a worthwhile cause

Beating some famous faces including politician Ed Balls (5 hours 31 mins) and newsreader Susannah Reid (5 hours 12 mins). The fantastic atmosphere on the day - The buzz along the entire 26.2 miles of the course with the crowds of tens of thousands of people shouting and cheering me on!

Last but definitely not least, crossing the finish line and realising I had beat my time from last year - I finished in 5 hours, 4 minutes and 34 seconds!

My race low-lights

Knowing I was only at mile 10 when then winner finished!

Being overtaken by a Rhino (twice!)

Not quite beating other famous faces including Gordon Ramsay (4 hours 26 mins) and James Cracknell (2 hours 59 mins - but then he was an Olympian!)

The realisation at mile 20 that I still had a long way to go!

I'll be having a rest next year, but perhaps someone else could take up the baton and run the London Marathon for the HSP support group. *The miracle is not to finish the race.... The miracle is to have the courage to start.*"
Go on - Give it a go!!

www.virginlondonmarathon.com

Sophie Pritchard

Chairman's Column

It was great to see so many of you at our AGM back in June. It's always good to have the opportunity to catch up with friends old and new and our three speakers were very interesting. The minutes of the AGM are included at the end of this Newslink. Since our last edition life has been as hectic as ever but all in a good way. Can I use this as a feeble excuse for this edition being slightly overdue?

I've just returned from a trip to Glasgow where I was helping the Salisbury FES team to demonstrate their equipment at an FES convention. I made some useful contacts and have hopefully persuaded PhysioFunction, who have addressed us at AGM, to write a regular column in our Newsletter. Watch this space. Whilst discussing Physiofunction, have a look at the Forthcoming Events section. You'll notice that they are providing the opportunity for people to have assessments and experience some of their services (which include FES) free of charge. This will be of particular interest to anyone from the Northampton area.

I was lucky enough to attend the final day's athletics at the Paralympics which included Oscar Pistorius winning his 400m gold medal. I'm so pleased I went, it was an incredible experience, an opinion echoed by everyone else I've spoken to who attended.

Following a competition organised by Aerobility, the charity I do my flying with, I was the first reserve to fly an aeroplane over the Olympic stadium at the opening ceremony which would have been a great opportunity to get HSP mentioned to an audience of a few billion. Nearly!!

Talking of Aerobility, I have now reduced my commitments with this charity and so from now on, all my voluntary efforts will be focusing on HSP.

At the end of August I attended all four days of the Bournemouth Air Festival and I'm aware a few other HSP members also enjoyed this event. The highlights for me were the Battle of Britain Memorial Flight, the Vulcan and of course, The Red Arrows. It is an annual event and I would recommend it to anyone, it is free and the disabled parking facilities are excellent.

While discussing flying I must congratulate Lorraine Saupe who recently flew solo following her flying scholarship at Wellesbourne. Good luck to Mark Tomlinson (Todd) who is beginning his flying scholarship at the beginning of October at Old Sarum airfield near Salisbury. Mark will be flying Microlites and I'm hoping to join him for a drink on more than one occasion during his stay down South. Who'd have thought we'd have so many aviators within the HSP Support Group?

In preparing for the future, much of my time and energy has been going into making my garden more disabled friendly. Raised beds, ramps, pathways and even a pond have or are being constructed. I'm very lucky to have a friend who is helping with most of this but I do as much as I can. My biggest problem seems to be not knowing when to stop, the consequence of which is usually a day or two of intense fatigue. It'll all be worth it in the end when I'll have full level access both inside and outside my house now I'm increasing my use of crutches and scooters/trikes.

I'm delighted to see how busy our Facebook site has become with members from all around the globe. If you haven't yet discovered it, search for 'Hereditary Spastic Paraplegia's Unite'

You'll notice that we have welcomed a few new members to the Group since the last edition. Just the usual reminders to all members, old and new: We are always after volunteers to help with various tasks. Some of these tasks can be very small but if anyone is interested in a committee position we'd be very keen to hear from you. New blood and consequently new ideas can only be a good thing.

I look forward to seeing some of you at Devon and Milford in the near future.

Ian Bennett

Secretary's Spot

CAB benefit advice at home

For a few years now Carolyn has been an associate member of the local Multiple Sclerosis (MS) group in Weymouth. We go to meetings with the group fairly regularly and we also occasionally go out on trips. At one of the meetings in the last couple of years we had a speaker who was from the local Citizens Advice Bureau (CAB). He was principally talking about the benefit system and some of the proposed changes to it (these are the changes now being implemented).

As a result of this talk and thoughts about other benefits for members the MS group has set up and funded an arrangement with the local CAB which allows a CAB advisor to go

and visit MS members in their homes to give them benefits advice. This has resulted in members being able to make more claims for benefits. Over the 18 months that the arrangement has been in place it is estimated that the members of the local group have been able to claim benefits in excess of £90,000 in addition to what they were claiming before.

While this arrangement of local visits has worked well in our area of Dorset there is no clear way to see how we might do this within the HSP Group nationally. This is mainly because the CAB are in fact a series of over 200 independent local groups and there is no way of making a national arrangement with them.

Within the HSP committee we thought long and hard about this and we have decided that we could allow members to claim grants to meet the cost of a visit by a CAB advisor for the purpose of giving benefits advice.

Members would have to make arrangements with their local CAB for such a visit. Members would pay the CAB for this and the HSP Group will then give a grant for the expenses incurred in the home visit. Application forms for grants can be obtained from the web site: (http://hspgroup.org/index2.php?option=com_content&task=view&id=93&pop=1&page=0), or from any Committee member.

Dave Harris

Useful Information

A Super New Cruise Ship

I've lost count of how many cruises my wife Carol and I have made (nearly 30), but our most recent was definitely our best. There are 2 reasons:

1. The cruise-route chosen was one of our favourites, to the Baltic Sea, visiting Stockholm, Copenhagen, Helsinki, Tallin, Rostock and St Petersburg.
2. The ship was a sister to one of our previous favourites, the Constellation, run by American-owned Celebrity Cruises. She is the Eclipse (which first came to our notice when she did a "rescue act" by

transporting travellers who had been stuck in Northern Spain in 2010, when the Icelandic Earthquake's ash-cloud was preventing nearly all European air travel. (The people concerned were brought across to Southampton to continue their various journeys home).

Anyway, we boarded the Eclipse at Southampton in August 2011 (on my 72nd birthday) for this 14-day Baltic cruise, and we were thoroughly delighted by the Celebrity crew, the cuisine, the comfort, the entertainment, etc, but probably my greatest pleasure was from its accessibility. Every public door was fully self-opening, so that any wheelchair could glide through without even slowing-down. Our own cabin-door opened by means of an electronic card-key, and it self-closed once we had entered into the cabin. (Mind you, you would probably have to seek this particular facility by means of selection of an appropriate "disabled-cabin" with the suitable bathroom facilities.)

Many handicapped people on cruises will know that it can be a major problem on most ships to find more than a few accessible toilets, but on the Eclipse these were plentiful, and it was just a matter of pushing a white panel outside the door to gain entry, and then, when inside, to push an "occupied" switch.

We also utilised the offered free quayside parking facility for the whole fortnight, and a drive of only 50 minutes in each direction made this a wonderful relief to add to the "no-flight" basis.

I know that an increasing number of our members are now making use of cruising for their holidays, and enjoying them greatly, so if this article adds at all to your prospects I would be delighted.

John Moore Region 1

Members' Letters

The Before & After Syndrome

It's some years since I wrote a personal history note, but it has occurred to me that there may be some interest in focusing on my past

activities: before I was even aware of my future neurological deficit with the looming HSP. I had indeed been very lucky with a lot of my early lifetime experiences.

So, let's go back to when I was only 9 years old, when I was taken to Wembley Stadium to see the 1948 Olympics, at which my key memory was to witness that marvellous Dutch sprinter, Fanny Blankers-Koen win the 100 and 200 yards.

I lived my childhood and youth at Eastcote, Middlesex, which was linked to London by the Metropolitan and Piccadilly Lines, such that my early occupations in London were on a direct route on the Met line (usually non-stop through Wembley Park). Thus, it was an easy matter for me to visit Wembley Stadium for many international matches, also to 2 FA Cup Finals (including the Spurs "Double" success in 1962), to Amateur Cup Finals and Schoolboy Internationals. Neither was I averse to visit the occasional speedway match, or Greyhound racing. Close to the Stadium was the Empire Pool, which had been turned into an ice-skating rink, at which I attended Ice-hockey matches for Wembley Lions, but which, for 2 years became my regular Sunday haunt for personal ice-skating, where I was physically able to tear-around the outer part of the rink with gay abandon.

I played football for my youth-club, and, from age 18 onwards, was part of my office team, which regularly played in the London Insurance Offices Association league at weekends. It was this membership which granted me an amazing facility, in that, when the 1966 World Cup was approaching, all members of the LIOFA, which was affiliated to the Football Association, were offered season-tickets at half-price. Naturally, I took-up this offer, and became able to see all 10 of the Wembley matches, including the Quarter, Semi and 3rd place finals and the Final itself.....at a total cost of £16. (And, by the way, I was standing in a position where I could see that the ball DID cross the line for that critical England goal against Germany!)

Tennis, snooker and bowls were my other pursuits, the last of which I could manage was bowls until age 35.

I was educated at a well-respected Grammar School, Pinner County, regarding which 3 aspects may be worthy of mention:

1. Coincidentally, at different times, there were 3 musicians of eventual fame:
 - a) Ron Goodwin who was a composer and conductor who did much work with the Bournemouth Symphony Orchestra, whom I have viewed with an annual season-ticket at Portsmouth Guildhall.
 - b) A guy called Reg Dwight, who became Elton John, who joined the school 2 years after I left.
 - c) Another young man a few years later, also from the modern pop era, called Simon le Bon, who starred with Duran Duran.
2. I joined the School's Air Training Corps. Loads of marching each week, plus learning about aviation and armaments, which became useful at our annual summer camps at various Air Force bases throughout the country. Each year I became involved in some flights: on 2 of which I was allowed to take mid-air control in a Prentice and a Chipmunk. I also enjoyed the rifle-shooting, and twice won competitions, using "22" rifles.
3. My school-year contained about 90 girls and boys. About 19 years ago, 2 of my pals who lunched together in Regent Street spotted an incoming diner, whom they recognised as another former pupil, and this inspired them to get in touch with all other ex-school pals, and try to create a "Reunion Group". About 50 (including some overseas) were reached, and we do in fact have an ongoing annual reunion meeting every autumn.....some of the overseas members have attended when they have been over here.

Progressing on from my youth, I met my wife Carol at a party in "guess where".....a house on Wembley Hill. We married in 1961, and lived in Westminster (close to Carol's home-base of Pimlico) for 3 years. Whilst there, I cycled to work daily past the Abbey and Big Ben, then along the Embankment to the City. 18 months later we bought our first car, and I then drove to work along the same route,

where I was lucky enough to be able to park on a neighbouring bomb-site. (London, at that time, from my Moorgate office area to St Pauls and around was a mass of wartime destruction, which was soon to be phased into gradual redevelopment.) Whilst living in Westminster, I used to cycle to Tottenham for as many Spurs home-matches as possible.

Our son, Ray, was born in 1962, and we moved to Rayleigh, Essex in 1964.

Unfortunately Ray was never capable of walking alone. Medical opinion on him was a non-entity, and it wasn't until a specialist saw me walk into the hospital in Southend, and then took my reflexes, that the possible diagnosis of FSP (its then title) was offered. This was the first time that I had even heard of the title: I had never been referred independently with just my "funny walk", nor had any of my male predecessors, all similarly affected. Ray had continued to live with us in Horndean, then Clanfield in Hampshire, after which, 9 years ago, he moved into a nearby Nursing Home in West Meon.

Naturally, we had been fearful of another family birth giving rise to HSP, and it was not until our daughter Claire and her husband Paul arranged a consultation with a genealogist that they felt happy to try: the verdict being that if Claire was, as found, free of any symptoms, then it was extremely unlikely that she could carry them now.

And the remaining blessing is that we have 2 lovely grandsons, Harry and Charlie, aged 14 and 11.

Reverting to my present incapacity: I am now nearly 73. I hobble around with a frame indoors and in the garage and garden, but vitally need my wheelchair or my motability scooter to get around externally. I still manage to drive a car adapted with hand-controls. I tried the FES system a few years ago and initially enjoyed the benefit: just a pity that the knowledge of the system had not come to me earlier. After a few years my experience with it was that, the more I toned-up the power to get stronger leg-lifting, the more difficult it became to control my legs. So, sadly, that was that!!

John Moore Region 1

New member writes HSP blog

As a recent new member of the group, I was pleased to be given the opportunity to introduce myself, let others know about my HSP blog, and seek feedback. My name is Adam Lawrence, I am 38, I have SPG4 and I am yet to show any significant symptoms.

Since my mum's similar diagnosis when I was at school I have known that there has always been a chance that I had inherited HSP. Up until 2008 I didn't feel the need to find out, knowing that the longer I went without showing any symptoms, the more likely it was that I had not inherited the condition.



Adam Lawrence

As a boy I went to Scouts and enjoyed walking in the hills, particularly the Lake District, and cycling has always been one of my regular forms of exercise, enjoyable as well. I took the opportunity to enjoy walking pretty much every year, most frequently to the Lake District, between about 1989 and 2003. I used to cycle to school and still cycle to work, and I've done the London to Brighton ride a few times. I got married in 2007, and we found out in the summer of 2008 that we were expecting a baby.

Although I had been content with my own position, my wife and I decided to find out if I had inherited HSP to know if there was a chance that our child could have it. The confirmed diagnosis marked the real start of my journey to HSP, as that time my knowledge was principally: HSP is not a common condition, that the physical changes are slow and that there are no known cures. I needed to know more, and I started doing

some more reading around, primarily on the internet.

After a while I realised that I had forgotten where I had read some things, and I also knew that I would forget some detail of the physical changes that I would be going through, so I thought that I should keep a diary as an aide memoir for myself. With most of the information being on-line, I decided to keep my diary on the computer. At that time there was lots of hype about blogs, so I decided to make my diary a blog, starting in June 2010. You can read this at hspjourney.blogspot.co.uk/.

I set out with the objective of making two entries each month, which I've managed in all but one month so far. I'm noting down my symptoms and my thoughts about them as they progress, various information that I find, with links, and various observations that I make. I realise that I am probably not the only person trying to find out this information, and perhaps my diary would be of interest or of use to others as well. I would welcome any feedback that anyone has to make about my blog. You can post comments on the blog, drop me an e-mail (adam@idios.co.uk) or find a link to my blog on the HSP community on <http://www.rareconnect.org/en/community/hereditary-spastic-paraplegia>.

As a taster of the information side of things, at the moment, I'm trying to get my head round the various HSP research that's been published. After I posted a similar blog link on rareconnect I had a link to the PubMed website which indexes medical journals. I initially downloaded data in April, and have improved my search in August. I currently find 1142 different HSP research papers from 1946 to 2012, and over 4400 different researchers have contributed to these papers. I'm exploring this data at the moment, but the data highlights are:

The number of papers per year has grown over time, and there has been about 70 papers per year since 2006. The journals with the most papers published are; Neurology (66 papers), Journal of Neurology, Neurosurgery, and Psychiatry (47 papers), Journal of the Neurological Sciences (36 papers), neurogenetics (34 papers), American Journal

of Human Genetics (33 papers) and Archives of Neurology (30 papers).

The most published researchers are: Alexis Brice MD, Pitié-Salpêtrière University Hospital, Paris (47 papers), Dr. Alexandra Dürr, Hopital de la Salpetriere, Paris (47 papers), Prof. Giovanni Stevanin, Ecole Pratique des Hautes Etudes, Paris (38 papers), John Fink MD, University of Michigan, Ann Arbor (29 papers), Dr Evan Reid, Cambridge Institute for Medical Research (27 papers).

This is my most recent line of investigation, and apologies if I've not lifted the correct (or most up to date) details of these researchers from the internet. Interestingly the database makes a point of separately distinguishing the first name for papers. John Fink scores highest, being the 'first name' on 13 of those 29 papers.

To supplement this there's a handy summary of HSP research over the years on the SP Foundation website, written April 2012 - <http://www.sp-foundation.org/content/articles/State-of-HSP-Research.pdf>, which I've also detailed in a post on my blog.

Adam Lawrence Region 4

Dear all,

Before going to Japan many friends said I should be prepared for a high-tech experience. Evidently the western mind was thinking of personal communication systems that we are so reliant on nowadays, like our 'phones, pads and pods.

The high-tech we found was with, excuse me saying, personal hygiene.

If, at locations such as stations or shopping areas, there was only one public facility, this was always fitted as a disabled toilet.

Admittedly the Japanese ladies do prefer the French style 'holes in the floor', but there was usually a choice, often indicated by the relevant profile (sitting or squatting) adhered to the door for guidance.

Toilets usually doubled up as all-in-one 'go, wash and blow dry', machines, with even the option of a choice of temperature for the blow dry! This is so unlike the French Bidet which tends to be a separate bowl with only a wash facility, and never available as a disabled version.

To give you all an idea of the complexity of toilets please see the picture below.

Usually a disabled toilet has the extras of a higher seat and arms, to help with getting on and off and occasionally a rest for the back.

Japan certainly does things differently. You will see the silver coloured box on the arm which is there for your toilet selections, which connect to the box along the back of the seat. These include raising and lowering the seat!



The coloured buttons on the wall beside the toilet I did not have time to investigate as this was the only Ladies toilet in Arrivals at Nakita airport; and many others had also been waiting.

This technology was not what I was expecting, but in some respects more fun.

Jane Bennett Region 2

Dear all,

We thoroughly enjoyed a holiday in Istanbul, but if I had been in a wheelchair and not being able to walk the enjoyment would not have been there.

Yes, there were plenty of disabled signs, inferring that facilities were available, but in the six days I did not find one disabled toilet.

Plenty of parent & child facilities but not disabled. Hardly a ramp in sight.

Jane Bennett Region 2

Dear all,

I have been recommended an ankle fusion operation. Please contact me on 01932 860368 to discuss after effects if undergone by anyone.

Martin Lawrence

Mr I Bennett & HSP Support Group

Dear HSP Support Group,

I hope all is well with you, I imagine you are very busy with the upcoming Annual General Meeting. I wanted to thank you for the HSP Newslink you send which I enjoy reading very much and here is a quick update from us at the National Hospital for Neurology.

We continue to see an increasing number of HSP patients in the neurogenetics clinic and this has always been interesting and enjoyable for us and the patients too hopefully! We continually try and improve patient management and care, particularly with the complications of HSP such as pain and fatigue and in the area of orthotics and FES as we work with a very good orthotists team. We are particularly lucky to have Liz Redmond, our neurogenetics nurse who is invaluable to Prof Wood and myself. In the clinic we are particularly keen to see patients every so often, even if patients have not been seen for many years, to examine and go over problems and update them on developments.

We are also starting to offer a comprehensive diagnostic service with the development of a “HSP chip”. This chip is being worked on by a research fellow (Dr Cherry Liu, email: yo-tsen.liu.10@ucl.ac.uk) and sequences the known HSP genes in a single run where the results and causative genes can be found in weeks instead of months or even years by the traditional sequencing method. This is invaluable to patients as we want to offer it to everyone possible to improve clinical diagnosis and genetic counselling.

A further area that we are pursuing is the development of “HSP stem cell models” taken from small sections of skin from patients (about half the size of a 5p coin). This is an important area for the future

development of therapies and treatment of our patients.

We are always very keen to see patients in clinic as an expert HSP opinion and we can be contacted at the address below.

Best wishes and yours sincerely,
Henry Houlden and Nick Wood
Professors of Neurology and Neurogenetics,

The National Hospital for Neurology and Neurosurgery,
Queen Square,
London WC1N 3BG. UK.
Email: h.houlden@ucl.ac.uk

Forthcoming Events:

Region 4 get together

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

Afternoon tea Regions 1 & 2

Sunday November 18th 3pm – 6pm
Milford Day Centre
Jenny Commerford, a Yoga teacher, should be joining us
Contact Jane Bennett on: 020 8853 4089

PhysioFunction Open Day

Free appointments available

Free assessments and trials of:
Physiotherapy intervention and exercise
Functional Electrical Stimulation
Rehabilitation for upper limb
Rehabilitation for lower limb

Wednesday 7th November
Holiday Inn Express
Grange Park
Northampton
NN4 5EZ

Call 0800 043 0327 to book

New Members

We welcome the following new members

Claire Steel
Jersey
Region Ch Is

Malcolm Ronald
Ottery St Mary
Region 4

Philip Roworth
Nottingham
Region 8

David Stoops
Ireland
Region Ire

Margaret Calouri
London
Region 1

Rhiannon Jones
Cardiff
Region 6

Eric Thomas Amos
Stafford
Region 7

Melanie Lewis
North Devon
Region 4

Roy Myers
Merseyside
Region 9

Fay Cookson
Essex
Region 5

Neil Cuthbertson
Bedfordshire
Region 3

Tracy Peppin
South Wales
Region 6

If you are interested in contacting any of the new members listed, please contact the relevant area co-ordinator, or the membership secretary, who can then supply the necessary contact details.

HSP Support Group 2012 AGM Minutes Saturday 16th June

The Trident Technology and Business Park, Poseidon Way, Warwick

The Meeting opened at 10.30 am with an introduction from Ian Bennett.

Present: Committee Members; Ian Bennett, John Mason, David Harris, Stephanie Flower, Simon Hubbard, John Moore. The total attendance was 75 and Apologies had been received from six members.

The Minutes of the 2011 AGM were accepted as a true and accurate record. They were proposed for adoption by Richard Williams and seconded by Michael Jarvis.

There were no Matters Arising.

Committee Reports.

Ian initially introduced the Committee team and summarised that we have increased the Maximum Grant to £500, to assist members in the purchase of mobility aids, etc. The acceptance by more and more members to receive the Newsletter by email has substantially reduced our administrative costs. A very interesting “first timer” in money-raising was created by member Maurice Charge who sponsored a race in HSP’s name at Sandown Park, where around £1000 was raised.

- a) Help Line – Stephanie Flower. A continuing matter of answering members’ requests for help and advice throughout the year, but Stephanie declared her surprise that nobody has yet enquired into obtaining a dog through the Canine Partners scheme. She again stressed their enormous help and value. Stephanie also warned possible loss of a state benefit beyond age 65, where we must beware of the loss of Mobility Allowance in the Disability Living Allowance conundrum.
 - b) Simon Hubbard acknowledged Ian’s verbal introduction of him, regarding his keeping in touch with research teams.
 - c) John Moore spoke of his habit in recent years of taking cruises at this critical time of year, but also of his delight in being able to attend again this year. He mentioned his hopefully
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valuable work 3 to 4 years ago in telephoning all seemingly “unpaid” members, to reaffirm their membership and to consider switching to Direct Debit. He also applauded the successful hard work of Ian, John Mason and David Harris in an incredibly busy period of fund-raising, with a concluding pat-on-the-back for Ian, whose stepping into the role of Chair whilst also retaining the duties of Membership Secretary and Newslink Editor has been incredibly commendable.

- d) Membership now totals 344 plus 48 Honorary Members (being doctors, consultants, physiotherapists, etc.) We also have 149 contributors to the Facebook Group “H-S-P Unite”. Our increased signing-up to “Gift Aid”, regarding our membership and sponsorship contributions, has considerably aided our funds, as has the payment of our contributions by Standing Order. There followed a reminder that members should submit details of their Specialists’ functions and locations.
- e) Treasurer’s Report (John Mason). Accounts were given to members present. These showed an end-year balance of £26,619.20. Thanks were given to Sonya Mason for her ongoing work on the accounts, and to Theo White as Auditor. Acceptance of the Report was proposed by Ronnie Ferguson and seconded by Caroline Begg, after which unanimous approval was indicated.
- f) Secretary’s Report - David Harris summarised the groups achievements for the year:
1. Ten grants to members - more than previous years.
 2. Good income from donations etc.
 3. No requests for research support grants
 4. Ten years of meetings in both Milford and Devon locations!!
 5. Regular meetings each year in South Wales and Hitchin as well
 6. Widening range of contributions/donations
 7. Success in getting email group re-established

Election of officers for the year ahead.

David Pearce had decide not to stand for re-election but all other members currently holding posts had indicated that they were prepared to continue in their present roles if re-elected.

Position	Nominee	Proposed-by	Seconded-by
Chairman	Ian Bennett	Mike Jarvis	Pat Reed
Treasurer	John Mason	Richard Williams	Della Brookman
Secretary	David Harris	Richard Williams	Debbie Best
Helpline	Stephanie Flower	Barbara Kevan	Lorraine Saupe
Committee	Simon Hubbard	John Moore	Mark Tomlinson
Committee	John Moore	Caroline Begg	Mark Tomlinson

Any Other Business.

No issues were raised.

The AGM itself ended at 11.10 am and was followed by three excellent presentations. Our thanks again go to the Trident Technology team for their excellent supply of lunch and other refreshments, and for the entire co-ordination of the premises.

The Meeting closed at 4.30 pm.

Hereditary Spastic Paraparesis Research Update Autumn 2012

This is a brief update on our research activity at the School of Health Professions Plymouth University. We would firstly like to say thank you to everyone who has participated in our research, entered into discussions at support group meetings and shown an interest in our research.

We have had two projects published this year and submitted some others.

Muscle paresis and passive stiffness: key determinants in limiting function in hereditary and spontaneous spastic paraparesis

This study was published in the journal *Gait and Posture*. It looks at the causes of one aspect of walking in HSP: the difficulty in bending the knee.



Measuring walking using the 3D motion analysis

We found that the lack of knee bend can be explained by two main factors; weakness (also termed paresis) in the calf muscles and stiffness in the muscles on the front of the thigh called the knee extensors. The stiffness in the knee extensors that limited

knee bending was associated with changes in the mechanical properties of the muscle rather than the enhanced stretch reflexes characteristic of spasticity. Areas of muscle weakness and stiffness are symptoms that could be potentially targeted with physical therapy and exercises and we are planning to develop trials to look at the effectiveness of such exercises in the future.

Functional Electrical Stimulation in hereditary and spontaneous spastic paraparesis

This paper will be published in the journal *Neuromodulation* in the next few months. It looks at the immediate effects of Functional Electrical Stimulation (FES) on walking in people with HSP who are long term users of this device. It shows that FES can improve walking speed and reduce foot drop while walking. The study highlights that using the stimulation to help muscle activity around the trunk and hips may also be helpful with some people.

Other Studies in the pipeline

We have three other studies that we have completed and have submitted to medical journals. The first looks at factors affecting standing balance in people with HSP. The second reports on focus groups that we held with people with HSP, spouses and carers and healthcare professionals into service delivery for people with HSP. We will update you on these papers in future newsletters.

The effects of localised temperature changes on lower limb function and neuromuscular properties in people with hereditary and spontaneous Spastic Paraparesis

We completed this study earlier this year and have spent the summer analysing and writing up the results. The study looked at effects of temperature on walking ability in HSP. The study was driven by comments of HSP support group members who felt that their walking was often worse when they were cold and better when they were warm.

We cooled or warmed one leg on separate days and assessed the effects this had on walking and a range of measures of nerve and muscle function. The main findings were that cooling decreased walking speed more than that seen in people without HSP, whilst warming improved walking speed. Cooling had several temporary effects on nerve and muscle function including an increase in spasticity and weakness and a slowing of the speed of signals in nerve fibres. In contrast, warming the limb tended to have the opposite effects. The changes with cooling in nerve and muscle function seem to compound problems with leg stiffness and weakness already seen in people with HSP and made walking more difficult.



Cooling the leg and measuring calf muscle strength and stiffness

The findings suggest that walking may be helped by insulating the leg against the cold and / or warming the leg. We are now working with a company, NeoG, who make neoprene garments and portable hot packs. These garments were felt to be the most practical by the South West HSP Group.

Future Work

The next study aims to assess whether this more portable warming/insulating system can improve walking ability to the same

extent as we saw in our experiment. We also want to assess whether the insulating garment helps to maintain leg temperature and changes in walking ability after the warming packs have been removed. If this is the case it could be something that people could use every-day.

This study will take place at Plymouth from November – January and will involve two separate sessions separated by at least 3 hours. Hopefully, this means for some people we can do the study in a day, if it is more convenient for them. If you would like more information on taking part in our next research project please contact Amanda.

Contact Us

You will see that there is a name change in the team below! Amanda is a proud mother and got married in September. Her e-mail is the same for now – just to confuse everyone!



Finally, once again we would like to say thank you for your support and interest. If you have any questions about any of our work please contact us at the address below or we can discuss things at future support group meetings!

Best wishes

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