



HSP Newslink

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

Issue 15 – September 2008

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

Rolls-Royce fund raise for HSP



Over the past four years, through the auspices of Rolls-Royce's London donations committee, efforts have been made by the company to develop partnerships between its corporate headquarters in Buckingham Gate and various local community,

education and environmental groups. In addition, one-off donations are often made via sponsorship of a specific sporting event and this is the tenth year Rolls-Royce has taken part in the JP Morgan Chase Corporate Challenge.

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As always, this year's Challenge was held in Battersea Park over two evenings in July. 13,500 runners took part on Thursday 10th July, including a team of 27 from Rolls-Royce, all of whom completed a course of 5.6k (3.5 miles). The team was lucky enough to miss the torrential rain suffered by those running in the event the previous night, and, bar a couple of clouds, the entire run took place in brilliant sunshine.

Every year at this event the team raises money on behalf of two nominated charities. This year, Ovarian Cancer Action and the Hereditary Spastic Paraplegia Support Group were elected to receive its support. The team has managed to raise £3,400 which, with an additional contribution from the London donations committee means that each charity will receive a cheque for £3,200.

Editor's comments

Once again, please accept my apologies for the delay in producing this edition. I have been waiting until I have collected sufficient content from our members and I have to say a huge "thank you" to all who have contributed material.

I am going to continue this policy of producing newsletters when I have sufficient content, so please keep up the good work and keep those letters and articles coming in.

I have just returned from a week in South Africa where I joined Caroline Begg during her first week's flight training following her successful application to FSD. Also being trained is another young man called Matt who also has HSP but is not yet a member (I'm working on it). I'm sure you'll all join me in wishing the pair of them the best of luck.

Ian Bennett

Secretary's Spot

I've just heard that we've received a further cheque of over £400 from HM Revenue and Customs in respect of Gift Aid – obviously we're all doing something right – many

thanks to all of you who have filled the forms in. We are also about to receive a charitable donation from Rolls Royce of just over three thousand pounds following a charity event they did on our behalf (see front page)..

Other members are also pitching in to help keep our funds up – one couple recently asked their friends to donate to our HSP Group instead of buying them gifts for their 50th Wedding Anniversary and we got over £200 as a result!

In order to use the funds we have to best effect, the committee wants to give further grants to organisations doing research into our condition. We will contact those organisations who we know and have done previous research but we would like to know about any other research initiatives which are happening. Please let committee members know if you are aware of any such work.

Well – it's already over three months since we had another great AGM in June – more in other places in this issue. At the AGM we had a stock of "business cards" which contain information about HSP and about the group. The idea is that these can be handed to people who need to know a bit about HSP. You can give them to Doctors or other Health Practitioners or to friends or others who express an interest. You will find a number of these attached to this Newslink in a small plastic pouch. Use them in any way you can and please let us know if you find them useful.

And finally (to quote News at Ten) it is time for us to be planning another update to the Information Booklet. To do this well we need as much information from you as we can get. Are there things in the book which are now wrong? – have names or conditions changed? – are there new subjects or services which you have used which may be useful for others to know about?

Do please get out your pen (or keypad) and let us know – our members are always our best source of information.

Dave Harris

Useful Information

A guide for disabled people
Holidays in Britain and Ireland
Published by RADAR
Tel. 02072503222

www.radar.org.uk

This publication has to be purchased, but also may be available to view at your local tourist office.

GOWRINGS Mobility UK Road Atlas

Tel. 08456088020

www.gowringsmobility.co.uk

Map book in large size format showing positions of disabled toilets, hotels attractions and various other needs.

Accessible Scotland

National tourism agency for Scotland
Tel. 08452255121

www.visitscotland.com

Accessible accommodation throughout Scotland and includes visitor attractions. Gives detail on levels of disability.

Accessible Travel and Leisure

Tel. 01452729739

www.accessibletravel.co.uk

Holiday information covering the world.

Disabled Holiday Directory

www.disabledholidaydirectory.co.uk

Internet information for UK and Europe, where we understand that the places have been visited by the publisher.

The Rough guide to accessible Britain

Motability/Rough Guides Limited
Tel. 08009230000

www.roughguides.com

100 accessible places to visit and things to do in Great Britain

Access guide to London Theatres

The society of London Theatres

www.theatre-access.co.uk

Excellent guide with plenty of detail

ACCESS Travel

Tel. 01942 888844

www.accesstravel.co.uk

Holiday information throughout Europe

National Trust Access Guide

Tel. 01793817643

www.accessforall@nationaltrust.org.uk

Booklet on all National Trust properties with appropriate disabled information

Accessible Places to Stay

Tourism for All

Tel. 08451249971

www.visitbritain.com

Accessible accommodation throughout Britain and includes visitor attractions. Gives details on levels of disability

Disabled Holiday Information

Registered Charity

www.disabledholidayinfo.org.uk

Accommodation information provided for the UK has been researched by wheelchair users and carers.

Disability Directory

Annually published by LINK publishing LTD

Tel. 01179547350

Lists suppliers of disability needs.

Many thanks to Pat and Terry Reed for providing all the above information.

Trophic Electrical Stimulation (TES)

What is Trophic Electrical Stimulation?"

Basically, TES copies the underlying signals, which nerves in normally functioning systems, feed to the muscle, to keep it in good health. The repeated signal is the impetus for the muscle to rebuild itself, but this takes time. However, it can compliment many conventional physiotherapy techniques. Initial treatment builds up the red muscle, which is the first to break down in conditions of pain (e.g. arthritis), lack of use (e.g. athletes unable to train) or complete disruption of nerve supply (Peripheral Nerve Injury)" This I have quoted from The Lindens Clinic Brochure

I use the "Neuro4" Trophic Electrical Stimulation for Chronic Neurological Conditions. The stimulator has 3 programmes, I implement programme No 2 which is programmed to improve nutrition to muscle. I use 4 electrodes, 2 on the top and

2 on the bottom of each thigh. Positions are highlighted in the manual. My physiotherapist helped me initially.

The electrodes are connected to the stimulator with electrical leads; they in turn stimulate the thigh muscles in tandem for a period of 1 hour. Stimulation is controlled by increasing /decreasing the impulses, until there is a mild flicker seen or felt in the core of the muscle. I sit in a chair and watch television, usually two hours before I go to bed. It is the next day I feel the benefit as long as the day is not too strenuous.

The main benefit for me has been ease of walking. It has done very little for my balance or any other bodily function. I still keep a diary (Log Book, sounds more manly)

Fergus Palmer Region 4

Members' Letters

Hi, my name is Jane Hoyle and I am a new member of the FSP group, living in Devon. I am married to a vicar, have two children, 17 and 19 years, and two tiny hypoallergenic dogs. I work full time for Devon County Council, which I enjoy, and get to drive around the beautiful countryside (spot the Londoner!). Last year I joined a ladies barbershop chorus, which is really good fun.

I have had a diagnosis of FSP for about twenty years, and in the last five years I have started to use a stick to get about outside the home. In the past couple of years I have had several falls, including downstairs and into walls; my husband has suggested a bubble-wrap suit might be helpful! My brother also has the condition, as did my late father and paternal grandfather.

I have found the FSP group very helpful: the email system, the newsletter and website, and the southwest group meeting I attended in April.

I have a suggestion which might raise some funds for the FSP group without much effort, for those of us that use the internet. We are used to using search engines such as Google; if we use instead the **everyclick.com** search engine, a few pence will be donated to the FSP group each time. This will build up

more quickly if more people use it, particularly if you set it as your homepage or default search engine (under Tools/Internet options). Please have a look - <http://www.everyclick.com/janehoyle>

Thanks!

Jane Hoyle Region 4

Letter from Sally Langton

For some years I suffered from leg ulcers, and on one I had four layer compression bandages for fourteen weeks, as well as having fairly swollen ankles. When we moved into the Lawns Residential home I discovered that one resident had seen an advert for a Circulation Booster and her physio had recommended it. I was worried about how it would feel, and I tried hers. It is very interesting as you can feel (and see) the calf muscles contracting in turn. I bought one and have used it daily for 30 minutes, for about a year and the swelling seems to have gone completely.

Another letter from Sally

Some time ago I saw an article in the News Letter about Self Catheterising. I had been on Oxybutenin for some time but was still having to go quite frequently. I had asked the continence nurse what she thought, but after testing me twice she said I was emptying my bladder completely, so it would not work for me. She then put me onto Bladder Retraining scheme which was rather hilarious. You start by going once an hour whether you want to go or not. (Except at night). After about 2 days you increase the timing by half an hour, and when you are happy with that you increase it by two and a half hours, until you reach four hours which is considered normal, but you cannot go backwards. In spite of the Oxybutenin I was still having to go fairly frequently, so she prescribed Solifenacin which has made a big difference on me.

Dear Editor

A number of years ago I was aware that somebody in the group had begun to construct a HSP family tree and I wondered if there might be anybody with the tools and time to take this idea further. I have a

suspicion that, with a condition like HSP, a number of us might be “related” back in time. The links are likely to be very complicated and I guess it would only be possible to look back on an individual basis (for a number of people) to see if there is an historical link somewhere. Any Feedback would be of interest and I wondered if the person who made the first stab at this a number of years ago remains in our membership.

Thanks, Ian Smith

Dear Editor

Whilst I would hope that such an incident will not occur, I wondered if anybody has experience of damaging an arm, perhaps in a fall, and the consequences of such an occurrence on their mobility whilst things were healing. I just wondered what help might have been available from the local NHS and/or the local council. I certainly rely on my arms for getting around on my crutch or wheelchair indoors and out and suspect that any damage to either of my arms would be a “show stopper”, even with family support. Has anybody been through this?

Ian Smith

Dear Members,

This years HSP AGM was awesome even though I got absolutely drenched from when I rode my scooter 40 miles to get there! I thought the AGM was really interesting because the PTC124 was being talked about. I’ve talked to Ian about the PTC124 and he says it will only work if I have the Nonsense Mutation. So I’ve got to have a blood test to see if I have this Nonsense Mutation.

I’m looking forward to next years AGM. Hopefully it doesn’t rain this time!

All the best, Daniel.

Daniel Gibson Region 8

Dear Ian,

Hi hope you are well!

Thank you for sending me the ‘introduction’ pack. How extraordinary it is that H.S.P. is a

shared thing and I’m not the only person on earth who isn’t quite right.

Having read some of the stuff (including the newsletter) I wondered if anybody would be vaguely interested in cycling.

Whilst awaiting my diagnosis I cycled from Maine to Florida, USA on my own – Just strapping a tent and sleeping bag to my ordinary bike and stopping in various places along the way.

As you can imagine, it was quite tiring and hard work at times but possible.

(Without sticks or my bike I’m not very good at walking or covering any distance).

I’m well aware that a lot of people will think “So what” but maybe somebody may be interested.

I am quite happy for this to be passed on to everyone else who is in your/our! Support group especially if they are of the fairer sex, around our age and look like Faye Dunaway in “Bonnie and Clyde “

Yours sincerely

Jeff Smith Region 8

Dear Ian

Thanks to the HSP Group for the gift of the scooter. It has been great, now that the weather is much better, I can get out so easily now. Bobby, my wee dog loves it because we can go to the local park, and he just runs along side. I have met a few people who have scooters and we compare notes.

The one I have is like new. The previous lady owner had only bought it a few months ago brand new, but unfortunately her husband passed away. She was so nice, but she was still missing him so much. My uncle had come with me as his mum has a scooter so he knew all about them. She insisted I took her address and phone number, so as well as the scooter, I now have a new friend. Thanks again!

My daughter bought me a ramp, but unfortunately it’s too wide for the door. We have to strip the scooter right down and take out the base over my rather high door stop, then we build it up again. It doesn’t take long but I’ve been to my social worker to see

if they can suggest something, to make it easier. I don't know if anyone could use a brand new ramp that folds up and goes into a bag?

Anyway, thanks again.

Love Rose McColl Region 11

For Sale

A brand new portable folding ramp. Cost £100 but would accept £70. See Rose McColl's letter above for details. Contact Ian Bennett for more information or Rose's contact details.

Thunder and Lightning

I think we all have had the hoax e-mail offering untold wealth or prizes. Well my story started off a little like that. It was one evening in August when feeling a bit tired I went to bed early but decided to check my e-mails, and there was one saying that I'd won a competition and not being someone who wins anything, not even a £10 on the lottery I was just about to hit the delete button when I saw that not only did it have my name correct but also noticed that the Aero Expo, at Wycombe Air Park, that I attended as a helper for the BDFA was also mentioned. At this point I remembered entering a few competitions at the event. So, I read on further, even opening up the link.

Could this be true or a joke from a friend, well I did sleep well that night. The next morning I rang the number on the e-mail and spoke the contact given on the e-mail – Hilary Brown, Events and Sponsorship Co-Ordinator for Shell Aviation & Shell Marine Products.

The e-mail was NO HOAX; I'd won a trip to Cape Town, South Africa to fly Heavy Metal War Birds at Thunder City. The trip included return flights to Cape Town from Manchester with KLM and 2 nights accommodation in a 4 star hotel. Plus a Flight in a choice of their war planes. They have Buccaneers, Hawker Hunters and Lightings. Well that was an easy one for me, because during my many stays in hospital throughout my childhood my

favourite Airfix plane after the Spitfire was the Lighting!! So, the choice was easy, for me it had to be the English Electric Lighting, then Hilary asked when I wanted to go as I could take it any time before the New Year. Well, I know that November was the start of their spring, I decided to fly the Lighting on my 44th Birthday, the 20th November. Hilary made all the arrangements and kept me informed throughout until I set off on my once in a life time adventure.

I arrived in S.A. late on the 17th November with a car waiting at the airport to take me to my hotel for the week, the Protea Hotel, Victoria Junction just a 5 min walk (or wheel) to the vibrant Victoria & Albert waterfront. All the staff there were so helpful and service was great. The Hotel was themed on a movie set, and my room had a view of Table Mountain. On my birthday the staff presented me with 2 bottles of wine and a cake!!!

The next 2 days were spent exploring the wonderful and vibrant city of Cape Town. I could go on for pages telling you about the Mother city, but I'll save you from that and say – make Cape Town a place you should visit, especially as they are holding the World Cup there in 2010.

On the morning of my birthday, I opened up the cards my children and girlfriend sent with me and went down to reception. I skipped breakfast, as I was too excited to eat and had a few butterflies in my stomach. A driver was there waiting to take me the 30 minutes drive to the airport. Upon my arrival at **Thunder City** at 09h30 I had a pre-flight tour of our operational hangar where the sheer size and technical ingenuity the incredible heavy metal jets blew my mind.

I was fitted with a flight suit and helmet, and briefed on its oxygen and communication facilities before being taken through to the pilots briefing room, to meet my pilot Dave Stock. I then had to undergo emergency and ejector seat training.

Together, with my pilot we planned our sortie – which was

- a supersonic climb to 50,000 feet to marvel at the incredible sight of the curvature of the earth
- fast flight (pulling 'g's')
- aerobatics (loops, rolls, barrel rolls, inverted flight, vertical manoeuvres to name but a few)
- low-level passes over the dramatic Cape coastline

You don't fly the **Lightning** like a conventional aeroplane – you strap her to your back - this is the crème-de-la-crème of ex-combat jet fighters. She's a beauty, offering the incredible power and 'g's' of the supersonic jet interceptor.



I climb the ladder, with a lot of help from the ground crew, sit down and get firmly strapped to my seat... we are ready. Oxygen masks on, breathing OK. The ground crew remove the safety pins from our seats. 'Seat is now live, OK'. Start master on...a surge from the air starter and No 1 engine begins to burst into life and then a second whine as No 2 engine joins it. A few more checks then the canopy comes down and locks with a positive clunk. The pilot increases throttle and we jolt gently round to the take off runway....

'Clear to line up' comes over the air. We move onto the white centre-line. 75% engines, then 85%...The pilot announces 'OK, here we go'

The brakes are released and we suddenly surge forward. The pilot is reading the knots, and the gain (and grin!) is faster than he can read the speed....'we are at 100 knots already', but that was then, now it's, 120, 130...' (The nose wheel lifts) '165, 175...'

At 175 knots we lift off. The undercarriage comes up and the nose begins to point skyward. We are doing about 450 knots now at an angle of about 70 degrees; I have by now become quite a snug fit in the back of my seat! Clearing the end of the runway we perform a barrel roll and carry on upward. 'WOW'

The coastline is now clearly visible below us, dark green landscape separated from deep blue sea by pencil thin white of sandy coastline. Air traffic control bursts over the intercom, 'Bravo, Bravo, Delta you are cleared to 45,000ft'. I look at the altimeter, 18,000ft already; the rate of climb indicator is spinning madly. We pull hard left at 4G, making me feel as though I am being squeezed into the airframe then we bank right, 30,000...35,000ft.

Airspeed is now close to Mach 1. 'Feel for the bump as I engage reheat on No 1 engine'...I here a muffled thud as my seat reacquaints itself with my back in a polite if firm manner. 'Now for No 2', thud...hello seat. The airspeed indicator hovers briefly around Mach 1, the airframe vibrating, then silence and the IAS jumps to about M1.25.

45,000ft now and the world looks very different. The horizon is a pronounced curve of light blue becoming progressively darker until directly above, a circle of black sky appears, and with it, the edge of space. Dave, my pilot now provides me with yet another perspective by inverting us! Mmmm.

Descending, we go supersonic once more. We begin to turn, the airframe vibrating, 'It doesn't really like turning supersonic'...but then who does? Descending still further, looping, turning and rolling, eventually we are at sea level hurtling along the coastline,

500ft high at 600 knots, and the sea just a blur.



Sadly the fuel gauges remind us the funs over and we need to go home. We touch down with about 600lbs of fuel left in each of the main tanks, the ventral tank sucked dry long ago. Arriving back at the hanger, it's all stop, canopy up and ladders on. I climb down and it occurs to me I'm completely exhausted. People who know me will tell you that I can talk non-stop especially about flying, but I was the first to admit that this aircraft took the words right out of my mouth.

The pilot, owners of Thunder City and Francois Smit, General Aviation Manager of Shell Oil later said they think I was the 1st disabled person to fly the Lightning supersonic. Maybe I should check it out with the Guinness Book of Records!!!!

Francois then took me back to Cape Town, where we had a great meal on the waterfront and talked for the next few hours about my adventure over a glass or 3 of South African Red Wine.

I would like to thank Hilary and Francois from Shell Oil, for all that effort in the smooth running of my adventure, All the people at the Hotel for making me feel so welcome and the surprise on my birthday, and everyone at Thunder City for all their efforts in making my birthday a once in a life time adventure.

Chris Leigh Region 9

Regional News

Region 9 Meeting

For members in and around Region 9 a meeting has been organised for Sunday 19th October.

This meeting will be held in the Red Rose suite at Ewood Park, Blackburn, from 10-30am until 4-30pm.

There will be a presentation from Carol McFadden and Wendy Watson, informing us about Functional Electrical Stimulation (FES) services in the North West. They will explain how FES works and how it can be easily administered, and there may be the opportunity for some of our members to have a quick trial.

The main objective of this meeting is for members to meet informally with other members of the group. This will hopefully be the first of regular gatherings in the North West.

If you are interested in attending or require any further information, please contact John Morris by any of the following methods:

Email: joka@madasafish.com

Tel: 01539 821870

Huge thanks to John Morris and his family for organising this event.

Forthcoming Events:

Region 4 get together

Saturday November 15th 2pm onwards
The Dartmoor Lodge Hotel – Ashburton
All members welcome. For further details contact Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday November 15th 3 – 6 pm
Milford Day centre
Anyone interested in attending, please contact Jane Bennett on 020 8853 4089

Region 9 meeting

Sunday October 19th 10.30 – 4.30
Red Rose Suite, Ewood Park, Blackburn
All members welcome. For further details Contact John Morris on 01539 821870

Mobility Roadshow

4th, 5th & 6th June 2009

Kemble Airfield near Cirencester,
Gloucestershire

Open daily 10am free admission and parking

www.mobilityroadshow.co.uk

New Members

We welcome the following new members:

Miss Hannah Smith
Shrewsbury
Region 7

Mr Peter Scarfe
Witney
Region 3

Miss Sharon Inglis
Suffolk
Region 5

Mrs Jenifer Hobson
Worcestershire
Region 7

Miss Tamsin Rowlinson
Hampshire
Region 1

Mrs Maureen Portch
Kent
Region 1

Mr Chris Leigh
Wigan
Region 9

Sandra Bateman
Porthcawl
Region 6

Mr David Cross
Newcastle Upon Tyne
Region 10

Mrs Sarah Rannard
Wirral
Region 9

Mr Jeffrey Smith
Bedfordshire
Region 8

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

Minutes of Annual General Meeting

Trident Technology and Business Park, Warwick - Saturday 21st June 2008.

Present: Committee members: David Harris; Stephanie Flower; Ian Bennett, being part of a total of **62 attendees**.

Apologies for Absence:

David Pearce; John Mason; John Moore.

In the absence of the Chairman, David Harris was elected as Chairman of the meeting.

Minutes of 2007 AGM

Duly accepted as a true record. Proposed for adoption by Jane Bennett and seconded by Ronnie Ferguson.

Matters Arising

There were none.

Committee Reports:

Secretary (David Harris) David Harris welcomed and thanked everybody for their attendance, including new members on a day when weather made travelling tedious. He gave a summary of the activities of the group over the last twelve months. In summary these were: 5 Regional meetings; Issued three members with grants to purchase equipment; Provided many volunteers for research at St George's; Improved communications and developed relationships in Europe; Pushed Gift Aid & claimed £336-69 back from treasury; Successfully encouraged members to pay by standing order; Constantly updated our website; Developed calling card following request from membership; Awarded £10,000 community award from Plymouth University for a research effort in the South West area.

Help-line: Stephanie Flower indicated her willingness to continue in her job for the next year and drew members attention to materials she had brought about Canine Partners.

Membership Secretary: Ian Bennett outlined our membership status, summarising that the overall count of 339 members contained 280 standard members, plus 20 Family Members and 39 Honorary Members (i.e. doctors, research fellows, etc.) Ian then displayed the national map-site, showing a spot where each member lives, indicating the concentration of those in the Southern Home-Counties, with the secondly most packed area being in the North-West, around Manchester and Liverpool (i.e. Region 9). He then reminded members of the ways the group could manage costs a) via Gift Aid payments and b) by paying subscription by standing order. Finally Ian asked if anyone present would consider volunteering as a Regional Coordinator for any of the areas in need of such person.

Treasurers Report: A full summary of the Group's financial status had been provided by John Mason and were distributed among members present. No significant matters were raised and the accounts were adopted by the meeting.

Election of Committee for the year ahead: All of the existing committee members, David Pearce, David Harris, John Mason, Ian Bennett, Stephanie Flower and John Moore had stated their willingness to stand for re-election, so it was just a case of Proposal and Secondment. Hands were duly raised as and where appropriate, and the following have been resultingly elected:

Position	Officer:	Proposed by:	Seconded by:
Chairman	David Pearce	Ronnie Ferguson	Debbie Best
Treasurer	John Mason	Mark Tomlinson	Terence Reed
Secretary	David Harris	Phil Burton	Lorraine Saupé
Membership Secretary	Ian Bennett	Caroline Begg	Patricia Reed
Helpline	Stephanie Flower	Ronnie Ferguson	Patricia Reed
Executive Committee Member	John Moore	Jane Bennett	Richard Williams

AOB

A special item was raised to suggest that the Group be re-named the Hereditary Spastic Paraplegia Support Group. The web site and Newslink already use this name – remaining items to change are stationery, Bank Account and Charity Commission registration. After a brief discussion, there was a unanimous vote in favour of making the change.

The AGM business was followed by three presentations, Dr Christopher McDermott of University of Sheffield on the research into support methods for HSP, Rudolf Kleinsorge of the German HSP group who introduced information on that group and its status and spoke about the drug PTC124 which had featured in the May 2007 issue of Newslink, and by Martyn Collis who gave a talk and showed videos describing the RYA Sailability scheme now available in many parts of the UK.

An excellent buffet lunch was provided and enjoyed by all.