



# HSP Newslink

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

**Issue 20 – May 2010**

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

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## Smiles and fun - shopping on wheels



Laura Branigan and Christine Snow enjoying the shops together with the help of Shopmobility

**I met Christine at the AGM last year and seeing as she lives near me I contacted her for a day out in March this year. I decided to reserve two scooters at shopmobility in the White Rose shopping centre in Leeds.**

The start of our day was disastrous when I fell into Christine in the car park knocking us both flying. I was also told the incorrect entrance (White Rose has several) meaning we had quite a walk to shopmobility to collect the scooters. Christine was a little apprehensive sitting

in a scooter for the first time but I felt confident that she'd find it liberating after the initial shock - as I did when I used a scooter for the 1st time at a mobility road show last year. After shopping separately for an hour we joined up for a coffee and spent the last hour zooming around from shop to shop - smiles all round. I recall that Christine described it as "fantastic" realising that she wouldn't have visited as many shops if it wasn't for the freedom a scooter brings. She's even thinking of buying one in the future.

I have a 2nd-hand compact portable scooter (Shoprider Capri) which I keep in the boot of the car - I wouldn't be without it. It's not a plush 'all-singing, all-dancing' type and doesn't work well on rough terrain or go up kerbs and struggles on sand etc. but it gets me about and helps me to be included on days out that friends have arranged. The liberation and independence is wonderful!

It'll be tested in a couple of weeks when I take it to Spain. I can foresee no problems as long as Ryan Air are kind - they promised they would be!

*Laura Branigan - Region 10*

**The day out that Laura has written about above has had a very positive effect on Christine's life and she has the following to say:**

## Turning point

Hi, Christine here, I felt I just had to share this with you all. Now I have to point out that I am a very independent person, I don't give up easily, "I can manage fine thank you" type of thinking.

I met up with Laura Branigan on this particular day at White Rose Shopping Centre, Leeds; we parked up near to the entrance of the Mobility Scooters. Laura was quite adamant & bossy with me, nicely though I have to say, and before I knew it I found myself sat in a scooter. We had a spot of lunch first, and a natter, then began our trip around the shops.

What a day that was for me, I actually really enjoyed it. We had such a giggle zooming around, it was Fun, we had a

giggle with one or two people also. I was happy & having fun, not making hard work of my life. The first thing I did when I got home was to phone my mum & dad up to share my day with them. They were so pleased, especially my Dad, bless him, he wants me to make life easier for myself.

I have to thank Laura, she was such an inspiration for me, and I'd like to be one for you too. I don't like the word disability, or say can't do that. I am doing exercise & stretching which you all know is a must, I now realise that I've got more energy to do it though. Also I want to do it; I'm no longer in my previous mindset. I can go out shopping, relaxed, happy, not exhausted, struggling with the negativity this condition can bring. This life is what we have, I intend making the most of it, I am going to be as able as I possibly can, and live with my true personality, not battling with it.

**So folks, this was my turning point!** I bomb around on a scooter now, quite content and I smile whilst doing so. I've thought of buying one myself, I haven't gone into it properly yet, I do know that you can hire them quite easily, so in the meantime that is what I do.

*Christine Snow - Region 10*

## Secretary's Spot

It's now mid May and after a spell of mixed weather it at least looks as if we're heading towards summer!

In my last piece I asked for members to think of equipment and devices they may be able to show to others at the AGM in order to better share ideas and experience among our members. There is still time if one or two more of you wish to show off your favourite gadgets, just let me know your name and what you intend to bring to our AGM.

We have been able this year to expand our programme of grants to some organisations doing research into HSP in addition to grants for members. Obviously we can only give grants within the funds we have available. At the moment we do get

donations from individuals during each year and it is mainly from these that we are able to fund our grants. We will give details of these items as usual at the AGM, but I would encourage all of you to think about ways that we can further increase our funds to enable us to provide even more support for the research into HSP.

That's all I have for now, but the AGM will soon be upon us so I look forward to meeting many of you on June 19<sup>th</sup> at Leamington Spa.

*Dave Harris*

## Donations made easy

I did someone a favour at an event recently lending them some equipment and afterwards they asked how much they owed me. Nothing really, it was a favour that I was quite happy to do. No, really, they insisted, we would like to do something in return. And then a bright idea: why not suggest a donation to the HSP Group. This is what you do:

Go to the HSP Support Group website <http://www.hspgroup.org>. If you can't remember the web address just put "HSP Charity" in to the Google search engine. On each page of our website there is a panel on the left hand side that looks like this:



Click on the "Donate online" button and this leads into the Just Giving website where you can state the amount of your donation (a minimum of £2) and how you want to pay. The options are a credit card or a PayPal account. It is easy to make a one off payment or you can set up a regular monthly payment.

From the HSP Group point of view we see a significant amount of money coming in

from this source. In the last 12 months we have received £1475 net of expenses so we are clearly a winner. Just Giving make it easy for fund raisers to set up their own pages and have donations directed to the HSP Group account.

So next time you come across someone who would like to make a contribution, direct them off to our website.

*John Mason*

## Useful Information

### Accessible Coast Path

"Thousands of miles of inaccessible and out-of-bounds coastline will be permanently opened up to the public with the implementation of the Marine and Coastal Access Act. This piece of legislation has now become law. This means that people will now be able to enjoy more of our coast without fear of trespassing or being diverted miles inland. Currently nearly 50% of the English coast has no public right of way, and so access is currently severely restricted in many places.

The Act requires a continuous coastal path around England, which will join with the Welsh Coastal Path and the existing rights of access in Scotland, to give the public the right to walk around the entire British coast. The new legal path is expected to bring unprecedented access to millions and vitally boost the rural economy.

The Disabled Ramblers (DR) has been involved in consultations on this matter for 2 years and has sought to ensure that new access provision will take into account the needs of mobility impaired visitors. This includes provision of accessible barriers and reasonable paths. It has, however, to be recognised that not all stretches can be made accessible due to very steep slopes and steps, but with strong representation much can be achieved."

The above is an extract from the November 2009 Disabled Ramblers magazine. It serves as a good introduction to a small task I got involved with as part of this major project. Carolyn has been a members of

the DR organisation for the last two or three years. I was contacted recently to assist by providing a small group of people from Natural England with an introduction to some of the paths around Portland Bill.

The surveying and planning of the future Coastal Path will, in large measure, fall to Natural England (NE) staff.

The DR were trying to show some potential NE surveyors that by making some terrain-capable electric vehicles available, that coastal footpaths could be made accessible at a lower cost than by providing major path laying solutions everywhere.

When I met the group at Portland Bill on a very cold and windy Friday afternoon in February, they had already spent the morning at Durlston Country park near Swanage. It was hoped that the Bill area could show a different set of access problems and allow them to see how the Tramper scooter could cope with them.

DR brought four Tramper vehicles in a trailer which were unloaded and ready by the time the surveyors arrived in their own cars.

We set off in an easterly direction at 2pm and covered the first half mile or so without much difficulty (apart from a couple of locked five-bar gates which had to be worked around). Shortly after this we got to an area which had previously been a quarry. The first challenge was a small escarpment (8-10 ft high) which we needed to descend to get into the quarry proper. There were a couple of narrow foot ways (think mountain goat) which did not look at all promising. Nevertheless, Robin Helby - who is the Chairman of DR (and also designed the Tramper) coaxed a couple of the vehicles down a hairy bit of path with a fall-away edge. We then noticed a slightly easier path down - this started a little further back and we had not noticed earlier as it was off to the side of the track we had been following. We got a couple of the other riders to get their vehicles down this bit with a lot of care.

On into the quarry area then with a lot of roughish stone paths and varying surfaces. We got through about another 200-300

yards before getting to a very steep, rocky and narrow ravine. This was the only available route and was considered too difficult to try. It was by now about half way through the time available, so we decided to turn around. Three point turns on narrow quarry paths were very interesting!

For safety each Tramper was attached to a rope for the climb back up the escarpment path - this was to ensure that they could each negotiate the "lip" at the top of the slope without falling back.

The trip back to the car park was then fairly uneventful, but all agreed, I think, that new challenges had been met and lessons had been learned about how Trampers could make otherwise difficult paths more accessible.

For those interested to learn more about the coastal access project, the following web link may be useful:

<http://www.defra.gov.uk/rural/countryside/coastaccess.htm>

## **Answer the door and the phone with one portable handset!**

### **Byron SX 304 doorbell/intercom and cordless phone**

If Carolyn is at home on her own, she finds it really takes her a long time to get to the front door if the doorbell rings. Often the caller has gone away by the time she gets to the door. It is similarly difficult for her to get to any given point at home (e.g. to go to a fixed intercom).

We were intrigued to see a new product which combines a DECT cordless phone handset with a wireless intercom for the door. This product the Byron SX 304 neatly brings these two functions into one phone handset.

Carolyn had already been used to carrying a cordless phone around home during the day. So we thought we'd give this new gadget a try.

The bell push and intercom unit fixes to the outer door in place of the previous bell push. The DECT phone "lives" in



Carolyn's pocket during the day and on its recharge base overnight.

When the doorbell rings, Carolyn just gets the phone out of her pocket and pushes a button – she can then talk to the caller and if need be she can tell them she'll take a while to get to the door.

To keep the device simple, the doorbell unit also contains the “ringer” which chimes loudly for about 45 seconds (unless you pick up the phone). So if I answer the door this can still be ringing while I talk to the caller! Additional handsets can be bought if you need more places to either hear or answer the door chime.

We've had it since January now and it seems to work fine for us!

*Dave & Carolyn Harris*

## Regional News

### Region 3

#### First ever meeting

My name is Della Brookman and have decided along with Ian Kitchen, to take on the role of Region Three coordinator as a joint venture. We both have HSP although, as of yet they haven't identified any specific gene responsible. So, apparently I have 99% probable HSP. Ian Has been a member since last year and very bravely did the bungee jump to raise money for HSP last October. You may have noticed him on the front page of the last newsletter.

Both of us live in the Hertfordshire area. Ian lives in Stevenage with his wife Louise and I live in Hitchin with my husband Roger, who will no doubt be involved as they see the opposite side of H.S.P. It is vital for all carer's and HSP'rs to talk to each other about their experiences. As it is often difficult to appreciate either side of the disease.

Since we have been involved in attending meetings, we have all met many lovely people and made lots of good friends. It has benefited me immensely as I know it has Ian and Louise too. My own experience of the meetings has made me

more confident and also made me realise that I am not alone, as it can very isolating, being a rare condition.

We will be arranging a social meeting in The Orange Tree pub on Stevenage Road, Hitchin Herts. We are thinking, maybe to meet in the bar there for about 1pm on the Saturday 7th August. Anyone is invited, as would be great to meet others from different regions. If you are interested in meeting up for a drink and a chat, or maybe even have an afternoon meal, please let us know, so that we can ascertain numbers. We will then be able to reserve a big table for us. The Orange Tree pub caters for the needs of disabled, so is ideal. They also have a pub garden at the back of the pub.

If interested, please let either myself or Ian know by E-mail.

ianpk2008@hotmail.co.uk

della\_brookman@msn.com

Hope to hear from you soon,

*Della Brookman and Ian Kitchen*

### Afternoon tea Regions 1 & 2

The April meeting could have been one of those rare occasions when I was refusing speakers! Following on from a suggestion made during the Carers' meeting in November, Amanda Edwards a neuro-physio from Farnham Hospital was contacted whilst Lorraine had suggested that two doctors from St Georges Hospital, Tooting joined us. The meeting was imminent and neither party had confirmed or declined and I thought that an afternoon of open discussion was ahead. Fortunately Amanda could not make April 24<sup>th</sup>!

With thanks to Lorraine we were joined by Karen and Ajith from St Georges Hospital. Workers at St George's have recently identified a new gene which may underlie the disease in some families or also in sporadic cases. This gene encodes an enzyme which works in neurons to produce substances known as 'neurosteroids' and patients with mutations in this gene may have altered levels of these compounds.

To facilitate this work Karen and Ajith wanted blood samples from both affected and unaffected people. Not everyone is happy giving a blood sample, but many thanks to all those that did and that was most people who attended.

I have asked Karen and Ajith to return next year, hopefully for the April meeting, to give an update on their study. The work is confidential, but they are happy to return with information.

The autumn Afternoon Tea is on Saturday November 20<sup>th</sup>. This will be a special occasion as we will be celebrating ten years of Region 1 and 2 Afternoon Teas. We have met in Chapel Lane for nineteen of those twenty meetings.

The seed that was sown at the AGM in Birmingham has certainly grown and is still germinating across the country.

In advance of the autumn, I would like to thank all those members who have been with us from the beginning, travelling the distance despite the often bleak (autumnal) weather and, especially, my family for their support. Thanks goes also to those members that have joined us but are no longer able to and those that have never been able to, but stay in contact.

The timing for the afternoon of Saturday November 20<sup>th</sup> will be the same, with Amanda Edwards joining us.

Wishing you all a very happy summer. Take care, especially if the temperatures increase.

*Warm wishes, Jane*

## **Region 4 Saturday March 20<sup>th</sup>**

A record turnout of 40 members met up at the now familiar and very hospitable Dartmoor Lodge Hotel in Ashburton. As is often the case, there was no formal agenda, members just enjoyed chatting amongst themselves and discussing various issues which may or may be not HSP related. We welcomed three new members, Carole Rowe, Lorraine Simcox and Sue Bailey who were meeting others with HSP for the first time. A couple of members took the opportunity to demonstrate their mobility aids for the potential benefit of others.

I must thank members for their generosity with the raffle. The raffle provides a bit of fun and I'm always amazed by the quality of the donated prizes and the amount we raise.

Following the meeting, 22 of us enjoyed the hotels facilities (the real ale is excellent) and stayed the night. The hotel always offers us preferential rates and the food and company in the restaurant on Saturday evening were excellent.

We regularly have members who attend from much further afield than the South West and it is always a pleasure to welcome anyone who may wish to join at future Ashburton events.

*Ian Bennett*

## **Region 6**

The third region 6 meeting was held at the Seabank hotel Porthcawl which had a dedicated conference room for us to use, with plenty of space and some pleasant sea views.

We were delighted to welcome some new members to the group. Tracy Whittington with husband Peter and daughter Libby who helped Lorraine with the raffle tickets and Terry Duffy who travelled from Maidenhead to his first meeting after joining the support group. The prize for the furthest travelled must go to Laura Branigan all the way from Yorkshire so a big thank you to all the long distance travellers for supporting the group. We were pleased to welcome Della and Roger to Wales for the first time.

Rachel Goodwin gave a presentation on the FES system and how it was being developed in Wales NHS. The hotel promised her a projector for her power point presentation but let her down at the last minute but she still gave a good talk with some very interesting information being passed on. I then gave the group a flip chart presentation (no high tech stuff here) on HSP and the genetic links within families. This was followed by the raffle and tea/coffee then some chatting. The hotel was not to the standard of the Atlantic where we held the meeting last year so all

those who stayed for the evening meal went to the Atlantic were the food is first class.

The Seabank has now changed hands and is owned by a coach company who use it for their coach trips to Porthcawl so will not be available in the future so our next meeting will be back in the Atlantic hotel as before. A big thank you to all who attended.

Next meeting date will be on the 25th September 2010 at:

The Atlantic Hotel  
Sea Front  
Porthcawl  
CF36 3LT

Look forward to seeing you there.

*Sandra & Peter Bateman – Region 6*

## **Forthcoming Events:**

### **Region 4 get together**

Saturday October 30<sup>th</sup> 2pm onwards  
The Dartmoor Lodge Hotel, Ashburton  
Call Ian Bennett on 01202 849391

### **Region 6 get together**

Saturday Sept 25<sup>th</sup> 2pm onwards  
Some members will arrive earlier for lunch - All welcome for lunch  
The Atlantic Hotel, Porthcawl  
Call Peter Bateman on 01656 788502

### **Afternoon tea Regions 1 & 2**

Saturday November 20<sup>th</sup> 3 – 6 pm  
Milford Day centre  
Anyone interested in attending, please contact Jane Bennett on:  
020 8853 4089

### **HSP AGM**

Saturday 19th June 2010  
10-15 am – 4-30 pm  
Trident Technology and Business Centre at  
Royal Leamington Spa

### **Motability Roadshow**

East of England Showground  
Peterborough, PE2 6XE  
July 1<sup>st</sup> – 3<sup>rd</sup>  
[www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)

## **New Members**

We welcome the following new members:

Anne Clifford Taylor  
Crewe  
Region 9

Martina McLaughlin  
Co Londonderry  
N.Ire

Christine Moran  
Co Antrim  
N Ire

Maxine Mellor  
Chesterfield  
Region 9

Hazel Molloy  
County Antrim  
N. Ire

Melanie Burnside  
Scarborough  
Region 10

Jackie Maclean  
Edinburgh  
Region 11

Pauline Bull  
Elland  
Region 10

Jennifer Gill  
Truro  
Region 4

Ray Martyn  
Nottingham  
Region 8

John Ball  
Doncaster  
Region 10

Roger Dymond  
Torrington  
Region 4

John Wigmore  
Basildon  
Region 5

Tracy Saxon  
Leicestershire  
Region 8

Kathleen Griffiths  
Hereford  
Region 7

Tracy Whittington  
Newport  
Region 6

Lorraine Simcox  
Newton Abbot  
Region 4

Susan Bailey  
Plymouth  
Region 4

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

# AGM Details

## Annual General Meeting & Conference 2010 Saturday 19th June

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

- 10.00 **Coffee & Welcome.**  
 10.30 **AGM**  
 11.00 **Physiofunction – Sarah Daniel**  
 Brief intro into the changes with HSP - how it affects muscle function and the consequences on movement.  
 The Physiotherapy Management (will break this down to specific areas i.e. posture, spasticity management, balance, walking, pain etc)  
 Demo of new technology including FES (PACE, Walkaide, Bioness) Musmate other orthotics.  
 11.45 **Break**  
 12.00 **Pat Reed**  
 12.15 **Open Session intro**  
 12.30 **Open session – demonstrations**  
 1.00 **Lunch**  
 1.30 **Open session – demonstrations**  
 2.30 **Dr Christos Proukakis – The Royal Free Hospital**  
 HSP – Scientific overview and new avenues of research  
 3.30 **Coffee and open forum**  
 4.30 **Close**

Physiofunction will be providing individual assessment slots throughout the day, members can contact Sarah Daniel's office on 0800 8600 138 to reserve an appointment slot, probably ranging from 15 minutes to half an hour depending what it is they would like to discuss.

Physiofunction staff will be on hand to answer the on the spot questions and will be available for consultations throughout the day and particularly during the open sessions.

### And finally:

**Carol Rowe**, from Exmouth, who attended our recent meeting at Ashburton, with her husband Mark, is planning to put on a Car Treasure Hunt to **raise some funds for our group**. Full details are not yet finalised, but it is likely to be on Sunday 15th August, with cars leaving at staggered intervals between 2 - 3pm, from a car park on Woodbury Common which is not far from Exmouth. Each car (min of 2 adults please) will be given details of the route to follow, all in rhyme, with questions to answer and things to look out for on the journey. It's not a race and 2-3hrs later, folk should arrive at a secret venue in East Devon where food and drink

will be available. The venue has its own car park, wheelchair access and everything is on the ground floor. This event will be open to anyone, not just HSP members.

Please tell your family and friends and encourage them to come along and join in the fun - children are also very welcome. In case it is important to you, on the route there are a couple of times where it is necessary to get out of your car and have a short walk to answer some questions.

If you would like the full details when they are available, or would like to take part on another date, please contact Carol Rowe on 01395 226905 or [carol@ex8.co.uk](mailto:carol@ex8.co.uk)