



# HSP Newslink

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

**Issue 19 – February 2010**

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

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## New member Ian takes plunge



New HSP member Ian Kitchen in a relaxed state just prior to performing a bungee jump benefitting HSP

The story starts on a plane coming home from my honeymoon in Jamaica last year. My wife, Louise, and I had both watched the film *The Bucket List* on the plane. When we got home we decided to do our very own bucket lists (a list of twenty five things to do before you kick

the bucket). I decided that number three on mine would be 'to do a bungee jump'. I only put this in for a laugh and never in a million years ever thought I would do one. However, a year later on our first wedding anniversary I was opening the present that my wife had bought me and

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was surprised to find out that she had bought me a bungee jump from Virgin Experience Days. I got very nervous when I saw it, and the realisation hit me that I might actually have to do a bungee jump. After a few months I plucked up the courage and booked it for Sunday 8th November. A couple of weeks went by and I suddenly came up with the idea that I would like to do my bungee jump for charity, so I went online to find charities that helped disabled people. After viewing a couple of sites I then googled the words 'Hereditary Spastic Paraparesis charity' and low and behold I discovered the charity. I was thrilled to find it as I knew my condition was a rare one and never in a million years thought there would be a charity dedicated to it.

I contacted Ian Bennett with the idea of doing the bungee jump for the charity and also joined the group, he gave me lots of help about who to contact and also about the just giving website.

I was really overwhelmed and touched when all the sponsors started coming in from people I had never met and soon smashed my original target of £150.

### **8th November 2009 - Jump day**

I woke up really really excited, I thought I would be nervous but I wasn't. I contacted David Britton and Della Brookman who I had been speaking to during the weeks leading up to the jump, to let them know that the jump was going ahead. David had kindly offered to film the jump for me for the group. I arrived at the jump site in Bray an hour early to book in for the jump. I then met up with David and had a nice chat. It felt good meeting someone that had a similar condition to me, I felt straight away that we had a bond or a connection just because we had a similar condition. It was a nice feeling that I could walk along side of someone that could empathise what I was going through and not just sympathise.

Shortly after Della arrived but I was getting fitted with my harness so I just gave her a wave. Then it was suddenly my turn to do the jump, I got in the cage and was told

straightaway that I would have to do my jump backwards as I was wearing a chest harness (due to my condition I couldn't use the ankle harness that 'normal' people wear). I felt panicked and scared as we made our way up to the top of the 160 foot crane and then the gate opened. I stepped out and got into position. Then the instructor said three, two, one, BUNGEE. I put one foot out and then bottled it and got back in. I closed my eyes and thought about the group and the money raised and I suddenly found my courage. I got up and jumped. It was a fantastic feeling, it was like the fastest rollercoaster I had ever been on and then the rope caught the strain and I let out a massive cheer. I was slowly lowered to the bottom and was greeted by my wife to help me up. I was feeling brilliant, I had done it. I then went and said hello to Della, not the best way to meet someone - thirty seconds after jumping off of a 160 foot crane but she was really lovely too. I watched over the video with David and he said I came down like Spiderman which I found funny. It was great to have met Della and David through the charity and know that we will become great friends. I got home and went straight to my bucket list and ticked it off, only to discover number sixteen was 'help a charity', looks like I got two birds with one stone.

Anyway, I have done the jump now and I would like to thank every body who supported me, the best wishes, and also to every body who sponsored me, again, thank you very much.

*Ian Kitchen*

## **Secretary's Spot**

I hope by now you've all got used to it being 2010!

Following on from my last piece I do want to remind all of you that the Group can provide grants of up to £400 to help with the purchase of equipment or other things which would help you to improve your day to day life. Please let us know if we can help you. There are application forms in

each copy of our information booklet, or any committee member can get one to you.

With the very cold weather we have all experienced lately it is worth taking a while to check that you have done everything you can to get through the worst of it next time! House insulation, boiler servicing, supplies in hand for if you can't get to the shops, replenishing things when you have used them so that they're there next time!

The committee is presently planning our AGM and one thing we want to do is to share our experiences of equipment and devices. Whilst we could invite a business to show their equipment, we've done that before and we think we might get more from promoting discussion and information sharing amongst members. So we are inviting members to volunteer to bring one or two items that they have found useful, and we will plan a longer lunchtime interval so that these items can be shown in and around the stairway atrium. If you are able to bring a couple of items that you find useful and show/discuss them with other members please contact me and let me know what you will show (max. of two items) so we can avoid duplication and get as wide a range as possible.

*Dave Harris*

## Grants Available for HSP Research Projects

As a group we know there are normally research projects in progress into aspects of the condition. At present there is a mismatch between the funds we have available and the cost of such projects - we can't fund a whole project.

As committee we want to use our resources to help wherever we can. We believe it is appropriate to use our funds to support research projects, so we are prepared to use the funds to provide the "day-to-day" costs which often allow such projects to run more smoothly. Examples of such costs might be: resupply of laboratory reagents, extra laptop, and other consumables.

We would like researchers to apply to us for grants of up to £5000 for funding to

support such projects. Written applications should be sent to the Secretary, HSP Group, 18, Lodmoor Avenue, Weymouth DT3 5AF, or by email to [dave@vadcar.org.uk](mailto:dave@vadcar.org.uk).

*Dave Harris*

## From the Editor

Thank you to members who've taken the trouble to contribute material to the recent editions of Newslink. Particular thanks must be expressed to Ian Kitchen for his marvellous efforts for the benefit of the Group that you'll have read about on the front cover. I know I speak on behalf of all of us here. Ian is a relatively new member and it wasn't only the fact that he was nutty enough to jump off a crane that impressed me, but also that he took the trouble to write about his experience and share it with us all.

There are a handful of members who do regularly contribute material and like Ian, deserve special thanks. Debbie Best, Pat and Terry Reed and John Morris come to mind, to name but a few. Without such input the Newslink would be considerably less interesting, it would certainly be much thinner and it would also become less regular.

Can I plead with all members to consider putting pen to paper? You may be surprised what range of topics is of interest to other members. You could discuss methods used to cope better with various problems associated with HSP. Unusual hobbies and activities are always interesting, or details of a recent successful or unsuccessful holiday are certainly items of particular interest.

Any material can be emailed to me or posted the old fashioned way.

## The Membership Sec butts in

Our members who currently pay their subscriptions by standing order are greatly appreciated, particularly by our treasurer. Our membership year ends on April 30<sup>th</sup> so those who don't pay by SO can expect a renewal reminder in the post in May.

Please let me know if you are interested in changing your payment method, standing orders are very straight forward to set up and help reduce our administration costs.

Another way you can help us reduce costs is to have future Newslinks delivered electronically as an attachment.

Approximately 100 members help us in this way, but possibly some of our newer members aren't aware of this option. Please let me know if you'd be happy to receive the Newslink by email in future.

The HSP Group has also benefitted from the Gift Aid scheme, last year our involvement in this earned us approximately £400. If you're a tax payer and not currently registered with Gift Aid, please let me know and I'll mail you the application form. Gift aid is simple; it doesn't cost you a penny, but generates useful funds for the Group.

We now have area coordinators for many of our regions and as a result regular local meetings are taking place across the country and in Wales. This is an important part of Group activities and I'm regularly delighted to learn of close friendships that have developed within our membership as a result of these activities. However, Region 3 is one area that is without a coordinator. If you'd be interested in volunteering to take this role on board I'd be very eager to hear from you. Region 3 covers Oxfordshire, Buckinghamshire and Hertfordshire and surrounding areas. If you live in this area and are interested in helping out, please let me or any other committee member know. Coincidentally, many of our new members listed in this edition are from Region 3. The role of a coordinator is simply to arrange an occasional meeting. This can be anything from two or three individuals getting together in a pub, to 40 people meeting in a village hall. Once you're up and running it's easy!

I look forward to seeing some of you at forthcoming meetings.

*Ian Bennett*

## Useful Information

### The Tom Wahlig Foundation

This is an organisation in Germany who raises money to fund research for the benefit of HSP. Tom Wahlig was the founder of this Foundation, inspired by his wife and son, both affected by HSP.

This year was the organisations 10<sup>th</sup> anniversary and to commemorate this they offered a €100,000 grant for research.

This grant was won by Dr Beate who is working with human skin cells taken from people with HSP. Further information can be found at <http://hsp-info.de/advanced-scholarship.158.0.html?&L=1#c546>

### Walking Aids

I'd like to write about a couple of mobility aids I have recently come across - namely Physiofunction and MuSmate.

I was introduced to Physiofunction when I attended the Enable exhibition in Coventry, November last year. They had a stand opposite the BDFA stand where I was helping out. Physiofunction is a specialised neurological physiotherapy organisation with clinics countrywide - in Northampton, Oxford, Bedford, Milton Keynes, Yorkshire and South Yorkshire.

My physio Charlotte has been trained at Salisbury in the use of FES. At one of our sessions she mentioned reading a magazine article about a walking aid called MuSmate which I sent off for and tried. It's a good alternative for those, like myself, not able to tolerate FES. I was amazed at how easy it was to walk with little effort and an improved gait. It claims, amongst other things, to help with walking faster and for longer periods - I think this would take practise. I hope to demonstrate the MuSmate at Ian Bennett's Devon meeting on March 20th. It's not the answer to our prayers and has limitations but I think it's worth a try and is an interesting alternative to FES. See what you think.....



To read more about the above, please visit:  
[www.physiofunction.com](http://www.physiofunction.com) and  
[www.musmate.co.uk](http://www.musmate.co.uk)

*Laura Branigan Region 10*

## Queen Elizabeth Foundation

AS HSP develops the loss of mobility can be double edged. For some the disability is not only in physical mobility, but the limitations in the lower limbs also affecting the ability to drive. For some the move to hand controls is easy, but for others an insurmountable hurdle.

When driving, or chauffeuring affected friends and family becomes difficult, knowing who or where to ask for help and information is not always to hand.

At the November Regions 1 and 2 Afternoon Tea Chris Kingsley, told us about the work of the Queen Elizabeth Foundation.

The Queen Elizabeth Foundation (<http://www.qef.org.uk/>) focuses on keeping people mobile. Mobility for some is motorised wheelchairs and scooters whilst for others it is cars and driving. Help with pavement scooters and powered wheelchairs comes in the form of trying both indoor and outdoor circuits. Car users have the opportunity to be tested to see if they are still fit to drive and, if necessary, assessment on suitable and appropriate fittings to cars, such as hand controls.

For those that chauffeur there is the opportunity to try different vehicles offering a variety of access, seating and equipment storage options

From the detail in Chris's presentation, and then paper copies supplied in a folder, there is a large range of fittings available. The Queen Elizabeth's Foundation does not make the adjustments to the car, but can recommend companies that do.

The list is extensive, but if anyone wants any details please either contact me or the Queen Elizabeth Foundation.

The Queen Elizabeth Foundation is based in Carshalton, but is part of the Forum of Mobility Centres throughout the country.

These centres all offer similar services. For details of where these Mobility Centres are located nationwide go to <http://www.mobility-centres.org.uk/>

The Queen Elizabeth Foundation Mobility Centre has free open mornings throughout the year, enabling interested individuals and groups to have both an illustrated talk and a tour of the Centre.

Thank you to all those members that venture out on the November afternoons to our meetings. The time of year, and weather conditions, are not always encouraging. We are always delighted to see you.

I know I am a little late, but we send you very best wishes for 2010.

Michael and Jane Bennett

## Members' Letters

Just recently, we have been in contact with a new member and his Wife. His name is Ian Kitchen and his wife is Louise. Lovely couple. :-)

Anyway, Ian put an announcement on Facebook, saying that he was going to do a Bungee Jump on the 8th November 2009 in aid of H.S.P. Straight away, people responded - H.S.P'rs and his family and friend's. Brilliant response.

We went along on the day and met Ian and Louise for the first time, face to face. Ian was a bit nervous, but that was expected really. Very brave.

Also, to my surprise, David Britton was there. He had travelled a long way to watch, take photos and support Ian in his quest.

He pulled off the stunt with confidence and was clearly exhilarated after. :-) Very brave. We are so glad we attended.

Thank you to Ian for doing this for H.S.P. I am sure it is appreciated by all. And thank you to Louise for allowing her hubby to do this for us.

Apparently, he wants to do a parachute jump next!!!

*Della Brookman.:-)*

**Dear all,**

Here I am again giving my account of the recent northern meeting held on October 11th.

It all started at 10.30am with teas and coffees and a chat, John Morris introduced himself for the ones who had not met before.

It was a good turn out (19 people). There should have been 21 but sadly Zoe Gibson daughter of John and Kath Morris and her husband Paul were at the last minute unable to join us as Zoe was poorly, all our best wishes went out to her.

Thanks go out to Dr Elizabeth Stoppard, from Airedale Hospital who works in Rehabilitation. She gave a very interesting talk on what she specialises in and answered quite a lot of questions that were put to her. She also gave a brief talk on how she had started out, all about her training and the Universities that she had attended to get her to where she is today.

We then went on to have lunch, and I'm sure I am speaking for everyone that was there that this was good. The venue was arranged by Gary Petersen one of Region 10 members and along with his partner they both made Sunday lunch for us all.

After lunch the Staff at Howden Hall Mobility Shop came to talk with us and brought a couple of scooters and wheelchairs that anyone could try if they wanted to and other aids to help people do various things in the house.

People then had chance to mix and mingle which I think always works. It is good to have speakers but "we" as you all know are the "professionals" were the ones with it.

It was now 4.30pm and time to go home, but it was a really good day and everyone enjoyed it. To see other people puts the word "HSP" into perspective.

I would again like many more of you to thank John, Kath and Zoe for the administration, Dr Elizabeth Stoppard and Howden Mobility for their talks and a very big thank you to Gary and his partner for the lunch and refreshments.

I would personally like to thank Mark Tomlinson again for being my chauffer as without him I would not be able to get to these meetings.

*Debbie Best (Region 10)*

## **Regional News**

### **Region 9 and 10 meeting Sunday October 11th**

Those who attended the meeting at Sutton in Craven on Sunday October 11<sup>th</sup> were treated to a most excellent informative talk in the presentation during the morning by Dr Elizabeth Stoppard. Patients in the Airedale area certainly are fortunate in having such a good consultant available and get far better support than we receive in Cumbria and perhaps that offered in many other areas as well.

Dr Stoppard, a niece of the well known Tom and Miriam, works at Airedale hospital as a member of the rehabilitation team, being one of around only 160 dedicated consultants in the country. She had trained in various branches of medicine before deciding to concentrate on rehabilitation.

Her talk reminded us of the discovery of HSP around 1880 and how it affects people. Others may not be aware they have it simply because they put up with problems, do not visit their GP or may be wrongly diagnosed. She continued to outline her work at Airedale hospital and in doing so involved all those present in questions and answers, allowing us to contribute and pass on comments.

The meeting came about following the one I organised the previous year at Blackburn and was attended by 19 members and friends. At Blackburn HSP member Garry Petersen suggested the use of his village hall as a venue. For many of us the village of Sutton in Craven was more like a city compared with the more rural locations we think of as a village. However it proved an excellent venue for our meeting as well as being well located for members in region 9 and 10 to get to. Garry did virtually all of

the organising and deserves big thanks for doing so. By comparison I feel as if I did little, merely contacted everyone about the meeting and taking bookings with the help of my daughter Zoe.

On the day unfortunately, Zoe was unable to attend and we were most grateful for the help and advice from her husband Paul who provided the technological equipment to ensure we had a good day. Paul had borrowed several items from his work at Lakeland in Windermere, not that Katherine or I (or most of those present) had any idea how to operate things. Lengthy mobile phone calls were necessary to set up the equipment.

During the day Garry and his partner Marilyn were busy working behind the scenes preparing a most excellent Sunday roast lunch after a welcome coffee and biscuits to be followed later by afternoon tea and cakes.

In the afternoon session, we had a display of equipment and talk from Howden Hall Mobility, a company based in Keighley. We were shown a variety of wheel chairs which members were allowed to try out along with walking aids, items to help in the home such as lever operated taps, tin openers etc. Howden Hall mobility are willing to help any members with advice or equipment and can be contacted by phone 01535 611776 or by email [howdenhallmobility@fsmail.net](mailto:howdenhallmobility@fsmail.net). At present their web site is still being prepared.

Everyone who attended felt the day had been very successful and those who had not been able to come had missed a well organised and informative day along with an excellent Sunday lunch. Dr Stoppards presentation had been very well received along with that of Howden Hall Mobility.

Unfortunately we were again unable to formally elect anyone willing to serve as representative for region 9 or 10 but the success of the day has led me and several others to consider arranging another meeting perhaps in the Autumn of 2010. Next time we hope to avoid any clash with other HSP meetings and are sorry our meeting this year was on the same weekend

as the one in South Wales. We already have one or two possible speakers in mind and would welcome any further thoughts both for speakers or venue.

Thanks again to Garry for all his work organising things at Sutton in Craven.  
John Morris

## Region 6 meeting

The Wales meeting for region 6 will be held on the 17th April 2010 in Porthcawl South Wales. We have a new venue for this years meet which will be at the Seabank hotel on the sea front. This is a much bigger hotel with plenty of parking spaces and a dedicated meeting room.

Full details are available on our new web site at [www.peterbateman.co.uk](http://www.peterbateman.co.uk) but for those without web access here is the main information:

The Seabank Hotel  
The Promenade  
Porthcawl  
CF36 3LU

Tel: 01656 782261

If you wish to stay please speak to Julia Dean and mention the HSP meeting to get a special room rate.

You can also contact me on  
01656788502 or 07702477026

All are welcome you don't have to be Welsh! or live in Wales if the weather is good make a weekend of it and enjoy Porthcawl.

## Forthcoming Events:

### Region 4 get together

Saturday March 20<sup>th</sup> 2pm onwards  
The Dartmoor Lodge Hotel, Ashburton  
Call Ian Bennett on 01202 849391

### Region 6 get together

Saturday April 17<sup>th</sup> 2pm onwards  
Some members will arrive earlier for lunch - All welcome for lunch  
The Seabank Hotel, Porthcawl  
Call Peter Bateman on 01656 788502

## Afternoon tea Regions 1 & 2

Saturday April 24th 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

## New Members

We welcome the following new members:

Barbara Jones  
Norwich  
Region 5

Maurice Charge  
Hertfordshire  
Region 3

Simon Hubbard  
Milton Keynes  
Region 3

Peter Hargreaves  
County Durham  
Region 10

Elizabeth Pywell  
Wallingford  
Region 3

Robert Millington  
Herefordshire  
Region 7

Ian Kitchen  
Stevenage  
Region 3

Terry Duffy  
Buckinghamshire  
Region 3

Jean Ithell  
Upminster  
Region 5

Valerie Spark  
Cumbria  
Region 9

John Greves  
Walton on Thames  
Region 1

June Coundon  
York  
Region 10

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

## Useful Contacts

	Email	Telephone No:
Richard Williams - Chairman Ash Tree Rise, Wendon Road, Saffron Walden, Essex, CB11 4HD	<a href="mailto:rushour33@gmail.com">rushour33@gmail.com</a>	01799 550534
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	<a href="mailto:dave@vadcar.org.uk">dave@vadcar.org.uk</a>	01305 772286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	<a href="mailto:john@jrmason.demon.co.uk">john@jrmason.demon.co.uk</a>	01225 761788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	<a href="mailto:FSPgroup@aol.com">FSPgroup@aol.com</a>	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	<a href="mailto:ian.bennett@tesco.net">ian.bennett@tesco.net</a>	01202 849391
David Pearce – Committee Member 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	<a href="mailto:pearcey david@yahoo.co.uk">pearcey david@yahoo.co.uk</a>	020 8551 2905
John Moore – Committee Member	<a href="mailto:john@moore108.orangehome.co.uk">john@moore108.orangehome.co.uk</a>	02392 592784
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	<a href="mailto:luckyjane82@hotmail.com">luckyjane82@hotmail.com</a>	020 88534089
Peter Bateman – Region 6 co-ordinator	<a href="mailto:pete@peterbateman.co.uk">pete@peterbateman.co.uk</a>	01656 788502