

HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 44 – May 2018

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

Dorset Adventurer to challenge five gruelling 5km peaks in eight days for HSP



Will ascending Mt. Kilimanjaro, Africa

Wimborne man Will Watson will be tackling the route to Everest Base Camp in September 2018. All funds raised will be donated directly to the H.S.P. Support Group, a registered charity who work very closely with people who suffer from hereditary spastic paraplegia (disability to the lower limbs).

“I didn’t want people to pay for something on my bucket list, instead any donations will go directly to such a deserving cause. The route will take me over some of the most arduous and hostile terrain on Earth, I’m so excited at conquering it.”

The journey through the mountains to Everest Base Camp takes in some of the highlights of the Himalayan mountain

range. The expedition begins at the World-renowned Lukla airport, classed as one of the most dangerous on the planet. Moving onward through Namche Bazaar, Will will take advantage of the last main town before heading into the mountains. He will pass the World famous Tengboche Buddhist monastery, at a height of almost four kilometres, and summits such as Kala Pattar, Gokyo peak and Chukkung Ri, reaching a maximum height of over five and a half kilometres.

Will has already successfully ascended Mt Kilimanjaro, hiked the Himalayan and Dolomite mountain ranges, competed in charity boxing matches for Wimborne ABC/Hit Fitness and has been studying and training for the past two years in preparation for joining the Royal Navy.

Will is also a high ropes instructor at Go Ape, Moors Valley Country Park, and participates as a youth coach with his local rugby team Wimborne RFC.

Donations can be made by visiting

www.justgiving.com/fundraising/everestforhsp

For more information, or if you are a business who would like to get involved in this exciting expedition, please contact Will Watson will.wally1@hotmail.co.uk or Jeff Webb appeditsolutions@gmail.com.

Chairman's Column



Hello Everyone, Last time I wrote Christmas was still fresh in the mind and we were moving into the new year. This time I have several important things to tell you about. There has been much work going on with the trustees getting ready for important changes which we need to make, which are described below. You will have no doubt read the notice of the AGM which will soon be with us, which I am looking forward to.

AGM Details

There are two changes to the AGM this year. Firstly, to make sure we are doing the best we can, after the AGM there is an opportunity for you to share (in small groups) issues that HSP gives you. We will focus on key issues to see if the group could help more. Each table will have a topic, and you can move between tables. The topics/groups we will look at are:

- Needs of people with complex HSP
- Needs of parents of young people with HSP
- Needs of young people with HSP
- Can the group be better at raising funds?
- Reducing the barriers HSP puts up
- What else could the support group do for me?

If you are attending the AGM, have a think about what issues bother you the most, or what information you find most difficult to get hold of. Also bring your solutions which may help others. We aim to find out what else the group could do to help you, and then work out a plan!

Secondly, whilst these discussions are going on, and for the rest of the day, there will be a second room with people you can chat with and hopefully try out relevant equipment. There are still confirmations to come in, but I hope to have (at least) a mobility company, an occupational therapist and a neurophysiotherapist with FES equipment and an exoskeleton.

In the main room, in the afternoon, we will have three presentations. Rebecca Schule is coming from Germany to talk about her research in the wide variation between peoples HSPs, Member Pat Reed is going to give us a carers perspective on HSP, and Fiona Shea is going to give us an overview of Occupational Therapists.

Tea and coffee are available from 10:00, and I expect that we'll finish the talks by 16:30. There will be a buffet lunch, as well as tea/coffee/cakes during the day, and that important time to chat with friends. I hope to see many of you there. Don't hesitate to come and say hello!

Revision to the groups constitution

We are required to work within the charitable objectives defined in our constitution. As the group has grown over the years we have become able to fund parts of research projects, but this is not listed in our objectives. Upon researching how to change our objectives we found that the Charities Commission advise charities to be set up as "charitable incorporated organisations", whereas we are set up as an "unincorporated association". To resolve both of these issues the trustees have written

a new constitution for the group. We have also taken the opportunity to bring several other items up to date. The key differences in the new constitution are:

- Trustees will be voted in by majority at the AGM, instead of by proposer and seconder.
- The objectives will cover all our activities.
- We can use postal voting, electronic voting and proxy voting at AGMs (although we are not proposing to do any of these straight away).
- Better definition of the types of membership of the group.
- Trustees will serve three year terms instead of the one year terms.
- The new setup reduces the risk to trustees and members in case of large problems.

In order to make a change to the constitution like this we require agreement from members, so one of the important steps at the AGM is for those present to vote to allow us to change the constitution. You can see both the current and proposed constitution on the groups website:

<http://hspgroup.org/index.php/governance-documents>. Let me know if you need a printed copy.

Assuming the new constitution is approved, all trustees will retire and need to be voted back in. To reflect the three year terms that trustees will hold, trustees will be elected for one, two or three years, so that the three year terms of trustees do not all coincide. The detail of this will be explained at the AGM. As trustees will need to be voted in by majority, we have all written statements saying what we aim to bring to the group, which are on the website. Please take a moment to read these before voting at the AGM.

Data Protection Changes

You may have heard that the General Data Protection Regulation (GDPR) replaces the Data Protection Act (DPA) in May 2018. One key difference between GDPR and DPA is that we must have explicit permission to hold your information and to contact you. We have prepared a data protection policy which describes the data we collect and what we intend to do with it. It also sets out your rights; <http://hspgroup.org/index.php/governance-documents>. We have also changed the membership application form to capture the consents for new members.

Please can you complete the revised membership form so we are sure:

- We have your consent to hold information about you
- We have the correct details for you
- We know your contact preferences

You can download the form from the website: <http://hspgroup.org/index.php/join-us>. On the form are several optional sections which you may choose to complete about your HSP. We will use this information to build a picture of HSP in the UK. Personally identifiable data will not be shared and there is no need to change your banking direct debit if you have already set this up.

And Finally....

In the last month or two I have set up a twitter account for the group - [@UKHSPGroup](https://twitter.com/UKHSPGroup). If you're doing something for HSP or spot anything relevant and interesting, then send me a tweet about it. I'm aiming to use this to promote our activities and any fund-raising activities, and highlight when HSP gets in the news.

Adam Lawrence

Editor's Column

As I write this, I'm recovering from a busy but very enjoyable weekend in Devon. I drove down from Dorset on Friday afternoon to Barnstaple to stay with some friends and in the evening we went to see a band in Bideford. On Saturday morning I made my way to Ashburton for the HSP meeting which I've written about later in this Newslink. On Sunday after leaving the hotel in Ashburton, I spent the day in Exeter before seeing two more bands play at a venue in the city centre. I finally arrived home at 1 am on Monday morning but it was an amazing weekend. I'm very keen to support musicians who generously support HSP at the Potato Pants festival and because I was in Devon anyway, it all slotted together very well.

Plans for this year's Potato Pants Festival are progressing well. I have now nearly completed the musical line up and we're currently sorting out catering arrangements and activities for children. You'll notice on the poster below that this year we've decided to open the festival on the Friday evening.



POTATO PANTS FESTIVAL

**High Mead Farm,
Ham Lane, BH22 9DR**

FRI 1st & SAT 2nd JUNE

Gates Open 7pm Fri & 2pm Sat, until 11pm

FRIDAY NIGHT Mikey Ball + Support SATURDAY The Winners of Ferndown Live Shannon White Harry Munk Emma Hardy Permanent Vacation Matt Black One Word Mikey Ball	HAPPY HOUR FRI 7-8pm SAT 2-3pm £2 per pint!	Fun afternoon activities for families/children Potato Pants Races <i>(all will become obvious!)</i>
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Bar supplied by local award winning Eight Arch Brewing Co.

FOOD STALLS

FRIDAY NIGHT ONLY Adults £5 Under 18's £2.50 Under 5's FREE	SATURDAY Adults £10 Under 18's £5.00 Under 5's FREE	RAISING MONEY FOR HEREDITARY SPASTIC PARAPLEGIA AND HIGH MEAD FARM
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TICKETS AVAILABLE ON THE DATE - A TICKET FOR SATURDAY WILL GET YOU IN ON FRIDAY FOR FREE

It's the Shakiest New Festival in town!

Tickets available from: High Mead Farm, Square Records - Wimborne

www.potatopantsfestival.co.uk

I look forward to seeing some of you there and hope that some can make it for the first time.

Although my daughter Jade will probably have run the London Marathon by the time you're reading this, she will still have to run the Edinburgh Marathon on 27th May. I'm very proud of how hard she's been training and her fundraising has been going well. So far Jade has raised just over £2400 (excluding Gift Aid) for the HSP Support Group. Her VirginMoneyGiving page is still active so please share it with all your friends

<https://uk.virginmoneygiving.com/JadeBennett>

I'm also very proud of my young friend, Will Watson who you'll have read about on the front of this Newslink. He's a young man that I met in the local pub, and has already filled his trousers with potatoes a couple of times in fund raising events for us. You'll have read that he has now decided to undergo a challenging hike through the Himalayas on our behalf.

I've mentioned in my Ashburton meeting summary later in this issue that Tracey Aggett has been awarded a Flying Scholarship from the charity FSDP. Tracey isn't our only successful applicant this year. New member Tim Matthews has also been awarded a Flying Scholarship and both Tracey and Tim will be learning to fly this summer. Congratulations to both of them. If you are interested in applying for a scholarship, you have until the end of the year to be in with a chance of being selected for flight training next year. For more information visit:

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

About a month ago I upgraded my mobility scooter, I still have the TGA Breeze, but I now have the off road version with wider wheels. I've already done a 20 mile trip on it and I love the freedom it gives me. The same applies to my two Kuschall wheelchairs which enable me to really enjoy some days out with the family and friends. I keep one chair permanently in the boot of my car and the other one remains in my house. I'm very lucky that my HSP has little effect on my upper body so self propelling a wheelchair isn't a problem. In fact, I see it as a challenge and a great form of

exercise. I've recently persuaded a couple of HSP members to swallow their pride and use a wheelchair and they haven't looked back. I will stress that a quality wheelchair is essential and my personal preference is for the rigid frame variety. Unfortunately, none of this equipment is cheap but what price do you put on freedom and enjoyment? You'll read an article later in this Newslink, written by a friend of mine, describing how he finally swallowed his pride and became a mobility

scooter user. He hasn't looked back and I hope that more HSP members will at least consider taking advantage of aids that can make our lives far more enjoyable.

Let's hope we have a good summer this year, good weather always has a tendency to raise one's mood. I look forward to seeing many of you at the AGM on June 9th or at Ashburton on October 13th

Ian Bennett

An On-line Survey for People with Hereditary Spastic Paraplegia (HSP) about Pain, Walking, Disability, Employment and Wellbeing

This is a summary of the findings of an on-line survey undertaken between September 2017 and January 2018. The survey covered pain, walking, disability, employment and wellbeing. Respondents also answered questions about their mobility allowing trends to be spotted with level of mobility. For more information look at my blog: <http://hspjourney.blogspot.co.uk/2018/02/2017-survey-results.html>

There were 222 respondents who completed the survey, predominantly from the USA and the UK, other places represented include Australia, Canada and Europe. Around half of respondents know they have other family members with HSP. Just under half of respondents knew the type of HSP they have. Most frequent types were SPG4 and SPG7.

Around half of respondents use walking sticks/poles/crutches/canes and use wheelchairs or mobility scooters. Around a third use a walking frame or rollator. FES is the mobility aid used by the least number of people. I have devised an "HSP mobility score" which then allows me to cross-reference mobility against the other questions in the questionnaire. The definition of the HSP mobility score is;

0. No mobility effects
1. Can walk without aids but some effects
2. Orthotics/AFO/FES and/or Sticks/Poles/Crutches/Canes some of the time
3. Sticks/Poles/Crutches/Canes and Frame/Chair some of the time
4. Sticks/Poles/Crutches/Canes most of the time
5. Sticks/Poles/Crutches/Canes all of the time
6. Rollator/Walking frame most of the time
7. Rollator/Walking frame all of the time
8. Wheelchair/Mobility scooter most of the time
9. Wheelchair/Mobility scooter all of the time

There is a reasonable spread between these mobility scores within the respondents. Around one third use sticks/poles/crutches all or most of the time (score 4 or 5), and the remaining results are spread fairly evenly.

In a change from previous years, 145 respondents also scored their mobility as it was in 2012. This shows a more rapid change in mobility than shown in my previous surveys which relied on my interpretations of text descriptions of changes over 5 years. Four respondents showed an improvement in mobility. The larger changes in mobility were most often from those now using a wheelchair all or most of the time.

Pain

My 2013 survey showed that just under 80% of people with HSP suffered from back pain, being significant in over a third of people. My 2014 survey showed that around a third of all medication being taken for HSP and HSP symptoms is for pain. I wanted to explore pain with HSP and from HSP symptoms to be able to quantify peoples' pain some more. Aside from two papers from 2016 there seems to be little published research quantifying what appears to be a relatively common symptom. To

evaluate how people describe their pain I selected the Short-Form McGill Pain Questionnaire (SF-MPQ-2) which has been used in a number of diverse studies examining chronic pain and acute pain.

211 respondents answered the pain questions. Of these 170 (81%) said that they get pain from HSP whereas 41 (19%) do not. The proportion of people who get pain from HSP is similar across the mobility bands. Those who use walking sticks all or most of the time get pain most often from HSP, and those who use frames all or most of the time get the pain least often from HSP.

Methods of pain control

The 170 people who get pain from HSP indicated the approaches they use to control pain. 13 respondents (8%) do not use any pain control. 157 people (92%) use at least one method of pain control, as shown in the following table, showing the most common methods of pain control, and the percentage of the 170 respondents with pain who use this.

Methods of pain control

Pain Control Method	Respondents	Percentage
Prescription medicines	103	61%
Physical therapy (e.g. exercise)	96	56%
Manipulation and massage	65	38%
Over-the-counter medicines	59	35%
Heat and cold therapy	49	29%

This shows that most people use medication, either prescription or over the counter, or physical therapy, either exercise, manipulation or massage to relieve pain. Heat and cold therapy, relaxation techniques and TENS machines are other methods used by at least 10% of respondents. The average number of methods used to treat pain is 3, and the most common number of methods used is 2. Three quarters (74%) of people use more than one method to control their pain.

Describing HSP pain

Respondents were asked to complete the Short-form McGill Pain Questionnaire (SF-MPQ-2). The questionnaire comprises a list of 22 different descriptions of pain, for example “stabbing pain”, and ask people to score their intensity of each item on a numeric scale from 0, “none” to 10, “worst possible”.

The total score is the summation of the 22 items, which can range between 0 and 220. I have also divided the total score by 22 to bring it back to a scale from 0 to 10. The overall average score is 76.4, which converts back to 3.5 on the 0 to 10 scale. Although the scale is different, the average value (3.5) is similar to the 3.4 reported by a published Brazilian paper using BFI scoring, and although the sample size is small, those who do not have pain from HSP score similarly (0.9) to the controls in the Brazilian study (1.0).

The pain score is highest for those using frames all or most of the time (6-7) and those using sticks all or most of the time (4-5). Pain is lowest for those using wheelchairs all or most of the time (8-9) and those who do not yet use mobility aids (0-1).

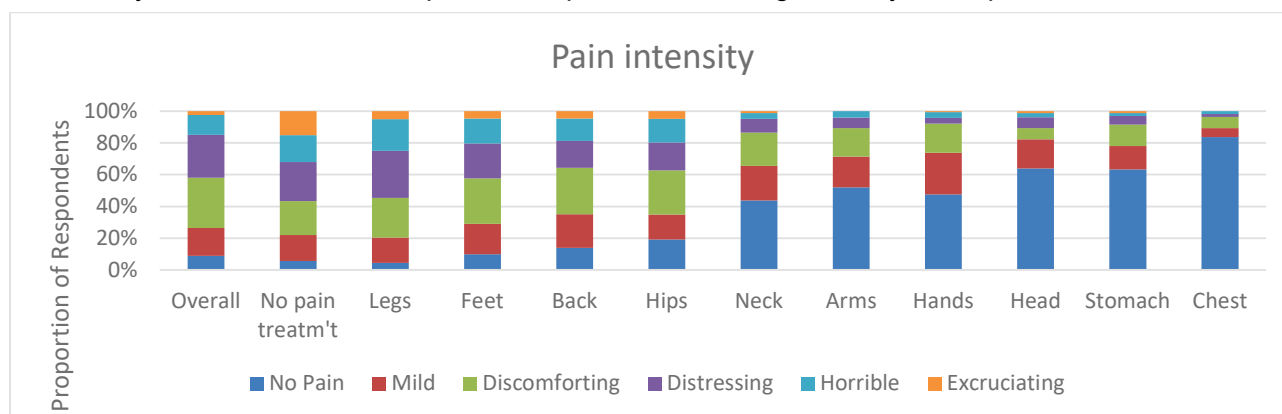
However, there are much larger differences between the 22 items, as shown in the table below, which indicates how many of the 116 people indicated more pain than none (a score of zero), and the average score (out of 10) for that factor for those people:

Of the 22 items, the description of the pain noted by the most respondents is “tiring-exhausting”, scoring an average of 6.9 out of 10 for 108 respondents (93%). “aching pain” is also noted by 108 respondents, with an average score of 5.7.

Other descriptions of pain affecting more than three quarters of those with pain are “cramping pain”, affecting 105 (91%) with an average score of 5.8, “tingling or ‘pins and needles’” affecting 102 (88%) with an average score of 5.0 and “numbness” affecting 99 (85%) with an average score of 4.8.

Over 95% of people who have pain with HSP have some pain in their legs, and over 90% have pain in their feet. For legs and feet the common descriptors for pain intensity are discomforting and distressing, accounting for more than half of respondents. Over 80% of people who have pain with HSP have some

pain in their back and hips. The common description for pain intensity is discomforting. These four areas of the body are similar to those reported in a published Norwegian study. The spread of data is shown:



Walking

Perhaps the most common symptom of HSP is impairment of walking. There are plenty of studies which evaluate walking speed and distance, evaluate gait patterns and muscle problems. The majority of the papers I have seen evaluate walking in a clinical environment. There is plenty of anecdotal evidence about how some environments are easier to walk in than others, and other anecdotal evidence about how walking requires concentration such that normal conversation is not possible. I wanted to explore perceptions around real walking environments and real distractions which people encounter, to examine if there are any trends.

I asked people to select how far they can walk from a picklist of options. These results generally showed things as expected – for example that people who can walk as far as they want to do not use wheelchairs all or most of the time, and people who are unable to walk are generally using wheelchairs all or most of the time. Generally, the more frequent the use of mobility aids the more walking distance is limited.

One third of respondents indicate that they get exhausted after a distance of more than 500m. The other answers score relatively evenly, with about one sixth of respondents in each of the other 3 categories (walk as far as wanted, unable to walk, maximum distance up to 10m, maximum distance up to 500m). I looked at a range of factors which affect peoples walking, split by these maximum walking distance answers.

Walk as far as they want

For those who can walk as far as they want, the factors which affect walking the most are: Being in a rush, Tiredness/fatigue, Going over uneven ground, and Carrying something. These factors affect around 90% of people.

When looking at the impact of each factor on walking, the highest scoring factors are: It being a cold day, Going down slopes, Tiredness/fatigue, Where stairs/steps are involved, and Going over uneven ground

Exhausted after more than 500m

For those who get exhausted after more than 500m, the factors which affect walking the most are: Tiredness/fatigue, Where stairs/steps are involved, Going down slopes, Going up slopes, Going over uneven ground, and Carrying something. These factors affect almost 100% of people.

When looking at the impact of each factor on walking, the highest scoring factors are: Where stairs/steps are involved, Tiredness/fatigue, Carrying something, Going over uneven ground, and Being in a rush.

Maximum Distance up to 500m

For those who can walk up to 500m, the factors which affect walking the most are: Tiredness/fatigue, Being in a rush, Going down slopes, Going over uneven ground, and, Where steps/stairs are involved, These factors affect all people.

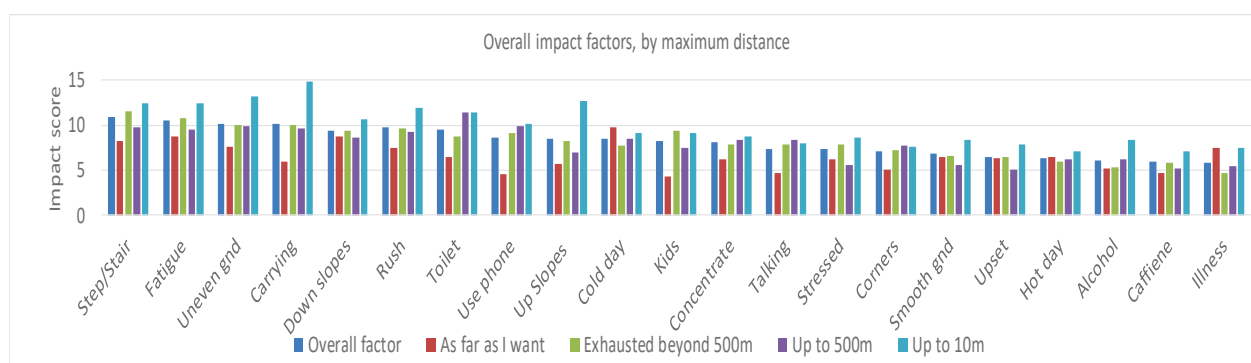
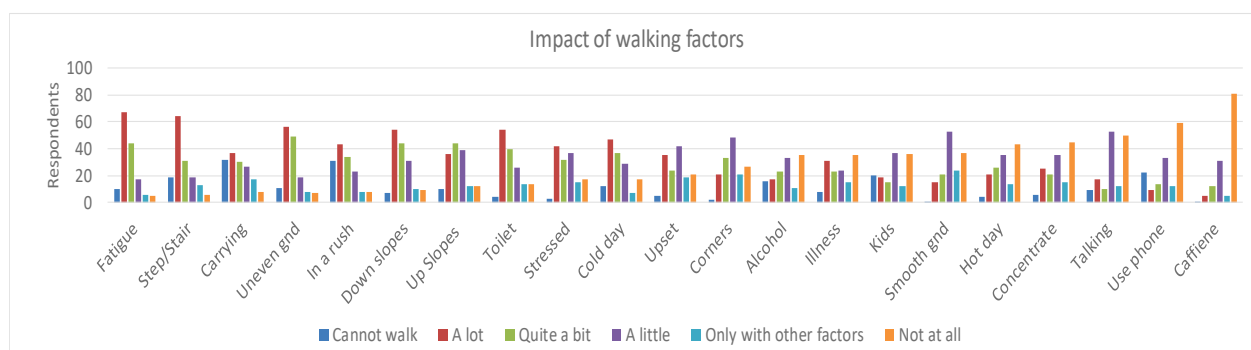
When looking at the impact of each factor on walking, the highest scoring factors are: Need to go to the toilet, Going over uneven ground, Using the phone, Where stairs/steps are involved, and Carrying something.

Maximum Distance up to 10m

For those who can walk up to 10m, the factors which affect walking the most are: Going down slopes, Going up slopes, Where steps/stairs are involved, and Needing to go to the toilet. These factors affect all people.

When looking at the impact of each factor on walking, the highest scoring factors are: Carrying something, Going over uneven ground, Going up slopes, Where stairs/steps are involved and Tiredness/fatigue.

These analyses are shown graphically:



Taking a broad view, looking at the results overall, the results shows that as a persons distance becomes limited the factors which affect walking each become more important. The factors which affect people walking the most seem to be:

- Where stairs/steps are involved
- Tiredness/fatigue
- Going over uneven ground
- Carrying something

Looking at combinations of factors, if people are affected by fatigue or tiredness, or they are in a rush, then walking is often more difficult. These factors are mentioned in combination with the widest number of factors indicating that they are key factors.

Occupation and Disability

Anecdotally, there are many stories about people having problems at work due to their HSP. I wanted to explore this issue some more to see if I could spot any trends. I set out a series of questions to obtain information about peoples occupation and employment.

I asked people if they considered themselves to be disabled or not. I then asked people about their age and employment status, if they are content with that situation, and if they have had to change jobs as a result of HSP. I asked people to describe their current and “pre-HSP” jobs by selecting from a pick-list of activity levels. Finally, I asked people if they thought they would have to change job in the future as a result of HSP.

Disability

219 people answered the question “Do you consider yourself to be disabled?”. 184 (84%) said they did and 35 (15%) said they did not.

Current Occupation/Employment Situation

217 respondents answered a question on their current employment status, selecting the answer which best suited from a pick-list.

the majority (71%) of respondents younger than 25 are students,
 the majority (64%) of those aged between 25 and 49 are working,
 the majority (66%) of those aged between 50 and 74 are retired (35%) or not working (32%),
 the majority (75%) of those of at least 75 are retired,

Overall, 53% of people are working or studying and 28% of people are not working, with the remainder retired. Of those who are not retired, there are approximately twice as many people working/studying as not.

195 of these people also indicated how content they are with their situation. Students appear to be content with their situation. Those in work, either full time or part time are generally content, closely followed by those who are retired. Those who don't work, work in voluntary sector or are carers are least content with their situation. The results showed that if employers are positive to HSP then people are more likely to be content with their situation, and if employers are negative about HSP then people are less likely to be content with their situation.

Reasons for discontent:

Respondents were able to give reasons why they were not content with their current situation. 54 respondents provided an answer. From this there are several emerging themes:

- HSP issues affecting doing the job, including mobility, fatigue, strength and balance (10 people)
- Feeling unable to work at all (10 people)
- Being made redundant or retired early from the job (8 people)
- Unhappy in current work/job (6 people)
- Wanting to work less, but unable to do so (4 people)
- Being unable to find employment (4 people)
- Wanting to work more, but unable to do so (3 people)
- General frustrations about the current situation (9 people)

The themes affecting the greatest number of people are either when HSP affects the ability to do their job, or when they feel unable to work at all.

Change in Employment

202 respondents answered about changing jobs or stopping working as a result of HSP. About two thirds of people have had to. The people who have had to change jobs the most are those who use walking frames all or most of the time, with more than 9 in 10 having to change jobs, followed by those who use wheelchairs all or most of the time at 7 in 10.

Respondents were asked the main factor which caused them to change jobs or stop working. 98 respondents completed an answer giving at least one factor. The main factors are:

- HSP offering physical limitations to undertaking work (67 respondents)
- Fatigue (23 respondents)
- Pain (17 respondents)
- Employer risk assessment/inability to alter workplace (12 respondents)
- Cognitive issues (7 respondents)
- Toilet issues (2 people)

I have put each response into as many categories as needed, noting that many respondents listed several factors, for example *"Fatigue, effort navigating the building"* and *"Constant back pain, difficult in walking, lack of energy"*.

This shows that the physical aspects of HSP are a key factor in around two thirds of respondents needing to stop work or change jobs. Fatigue similarly affects around a quarter of respondents, and pain affects around a fifth.

There were 12 respondents whose responses I have gathered under employer issues. These fell into two main groups, one where the respondent ceased to meet the requirements of their job. These were described as *"being high risk"*, *"being discharged"* or *"failing a medical"*. The other group was more about employers' attitudes or failing to adapt the workplace, described as; *"attitude of boss"*, *"they couldn't adapt my work post"*, and *"they didn't even want me driving into the parking lot"*.

I asked respondents to describe the intensity of their pre-HSP jobs. This showed that there were no clear and obvious trends in job types or job intensity, other than to note those with a current high use of mobility aids and very physical pre-HSP jobs who'd had to change jobs.

Consequences of Change

I asked respondents about the consequences of the change. 67 people responded in a way that I was able to judge the feeling behind the consequence described. There was a range of positive, negative and mixed consequences. Negative consequences account for about three quarters of responses, with the positive accounting for about one sixth.

By far the biggest negative consequence was financial, with about a third of respondents saying they had less money. Several (about 1 in 7) people said that they retired before they were ready to, and a similar number said they were more alone. Others commented that they were bored, frustrated or depressed and other that they were not making as much of a contribution or being a bigger burden. A few people said that they liked their current job less than their previous job.

Positive consequences included several describing themselves in a *"better situation"*, with others specifying less pain, less fatigue, fewer falls, and others saying they felt less of a burden on others.

A few respondents described having to start their lives over again, which I have taken to be a mix of positive and negative elements, whilst others balanced positive and negative factors in their answers, for example: *"lost independence, now i do not work i have less stress, less worry, less spasms, less tension headaches, less fatigue and i can now attend physio appointments"*, *"I'm a lot more isolated now but also very relieved, as I was very stressed trying to work with the disability. Now I can rest and manage the pain and sensory input so my life is a lot better for that."* and *"Money has changed, but I 'm glad I have more spare time"*.

Roughly two thirds of people think they will have to change jobs or stop working early in the future as a result of HSP.

Wellbeing

The results of my 2013 and 2015 surveys and other papers show that depression is a relatively common symptom for those with HSP. There are a range of personality types with differing outlooks on life. I wanted to investigate this aspect, but decided that there were too many factors to be able to isolate these in my questionnaire. Personality type questionnaires also contain a relatively high number of questions. Therefore, I elected to simply look at wellbeing.

I found 1 paper which covers wellbeing in HSP. A Norwegian paper in 2016 reported lower life satisfaction and lower mental wellbeing for people with HSP. I selected the 14 item Warwick-Edinburgh Mental Well-being scale (WEMWBS) to assess wellbeing because this assesses wellbeing in 14 questions, and there is a big dataset describing various population norms from Scotland and England.

172 respondents answered this question, with the average wellbeing score of 45.9. The scores ranged between 19 and 68. The average is lower than UK population norms, which is in line with the results of the Norwegian study. The average is still within the "average" definition, but is more than 5 points below the UK population norms of 51-52, suggesting a significant effect. The results are similar to those who perceive their health status as "poor". People with SPG4 are similar to the overall average score. Those with SPG7 may have lower wellbeing than others with HSP.

Factors which may be significant differentiators in wellbeing:

There are a number of factors where there is more than a 5 point difference between the average of each answer, which may be an indicator of a significant differentiator in wellbeing. These are:

- People who do not get pain from HSP have a better wellbeing than those who get pain from HSP.
- People who are content with the employment/occupation situation tend to have a better wellbeing than those who are not.
- People whose employers are not supportive of HSP situations tend to have a lower wellbeing.
- Those who can walk as far as they want have a better wellbeing, and those who are unable to walk are likely to have a better wellbeing.

Factors which are unlikely to be significant differentiators in wellbeing:

There are other factors where there is less than a 5 point difference between the average of each answer, suggesting they are unlikely to be significant differentiator in wellbeing. These are:

- By use of mobility aids. The average wellbeing score is similar across all mobility scores, and scores are within 3 points of the average.
- Those whose walking distance is limited are within 3 points of the average.

- The average wellbeing for those that consider themselves disabled and not are similar, and within 3 points of the average.
- Looking at employment category the results are generally similar and generally within 3 points of the average. Those who are carers with HSP appear to have a lower wellbeing score than other categories. People with HSP have a lower wellbeing score than the England average across the majority of employment statuses.

Acknowledgements

First and foremost, I need to thank all of the respondents who took time to respond to this survey, without these excellent answers this analysis would not be possible. Most of the recruitment has been through:

- HSP support groups, who I thank for letting their members know about my surveys,
- Many HSP groups on Facebook, whose admins I thank for letting me post about this.

Lily Rice Wins Silver

HSP Group member, Lily Rice, who featured on the front of the February Newslink, has recently won a silver medal at the World WCMX (wheelchair motocross) Championships in California.

Fourteen year old Lily from Manorbier in Wales was the only GB representative in the competition.

She turned in a stunning performance in the contest's women's division to claim a superb second place.



Lily proudly wearing her silver medal
Lily is now being hailed as a global leader in the fast-growing sport of WCMX.

She hit the headlines last autumn when she became the first female in Europe to achieve a wheelchair back flip, and only the second girl in the world to pull off the stunt.

The world's first backflip honour is held by former world champion Katherine Beattie, who Tweeted: "This girl is THE future of WCMX! I've never seen anyone rider like her."

Lily, a Year 9 pupil at Tenby's Greenhill School, travelled to the USA with her mum and dad Jenni and Mark and her 11-year-old sister Amber.

Mark said: "The whole experience was just amazing - the atmosphere, the riders and families for making us feel so welcome, and Lily has certainly made friends for life."

Riding in 27 degree heat, Lily went nervously into the qualification rounds, emerging in fourth place.

But the final saw her confidence soar and she pulled off some outstanding moves to emerge with a silver medal, just two points behind the eventual winner, local girl Alyssa Montenegro.

Mark said: "All the women rode well; we thought Lily took possibly a third place, but when they announced Santa Monica local legend Tracey G had bronze we thought Lily was out of the running."

A long pause heralded the announcement of Lily as the silver medal winner and, Mark said: "We couldn't believe our ears. We all cried tears of happiness.

"Lily was in a state of shock before the biggest smile we have ever seen. She was still buzzing 24 hours later."

Lily was followed throughout the championships by a team from BBC 3 and Mark said: "Even they cried!

"Once they had seen the atmosphere, the determination of the competitors young and old they were straight on the phone to their bosses telling them it needed to be aired on BBC sport.....so fingers crossed".

World champion Aaron Fotheringham - who donated his old WCMX chair to Lily - retained his title and watched Lily's performance closely.

Added Mark: "He was stoked to see his old chair put to such good use, and him and Lily were seen laughing many times over the course of the week...just magic! Who says you can't make dreams come true."

"Moving forward, the next event takes place in Germany in August, but more importantly, Lily wants to continue to encourage others into the sport and promote social inclusion."

Follow Lily on Instagram @hsp.me; Facebook Lily Rice WCMX and Twitter @LilyRice_WCMX

Ruth Davies

Useful Information



Calvert Trust Exmoor is the South West's premier outdoor activity destination for people with all types of disabilities, welcoming over 4,000 guests a year, with the philosophy of "At Calvert Trust Exmoor it's what you **CAN** do that counts".

Located in an area of outstanding natural beauty on the edge of Exmoor National Park, the accessible residential adventure centre enables people with disabilities of any age and ability to experience exciting, challenging and enjoyable activity adventures, together with their family and friends.

Calvert Trust Exmoor is **the only 5 star activity accommodation in the country**, and has also been accredited against the National Accessible Scheme as being suitable for older and less mobile guests, part-time wheelchair

users, independent wheelchair users, assisted wheelchair users, visually impaired guests and hearing impaired guests. You can read more about their accessibility from the accessibility statement on their website here:

www.calvert-trust.org.uk/access

Many guests are surprised by how much they can do at Calvert Trust Exmoor, as recent guest Sarah Davies put it: *"Just had possibly our best holiday ever. The food was gorgeous, the accommodation spotless and comfortable, and the activities, well, I didn't imagine myself doing half of what we did but we loved every minute."*



A break at Calvert Trust Exmoor includes a structured programme of exciting activities tailored to the specific needs of our visitors, specifically designed and equipped to cater for all. Activities on offer include climbing, archery, horse riding, wheelchair abseiling, carriage driving, sailing, accessible cycling and many others.



Other facilities on site included a fully accessible hydrotherapy swimming pool with high needs changing facilities, a Jacuzzi,

children's play area, games room, bar, sensory room and the Acland room, which is a fully glazed, elevated, communal area with fantastic views to the south west across Wistlandpound Reservoir, down the valley of the river Yeo and into South Devon.

The centre's fully accessible accommodation consists of ensuite single, twin and triple bedrooms including some with H-track ceiling hoists, as well as a number of apartments with open plan kitchen and living space, which can be booked on either a self catered or fully inclusive basis. Calvert Trust Exmoor also offers mobile hoists, shower chairs, electric beds, trembler pads, and other loan equipment to make all guest's stay more comfortable regardless of their disability.

Guests stay with Calvert Trust Exmoor for 3, 4 or 7 night stays, or can just come for the day.

Telephone: 01598 763221

Website: www.calvert-trust.org.uk/exmoor

Facebook: www.facebook.com/CTExmoor

Twitter: twitter.com/calvertexmoor

Registered Charity No: 1005776

Company Number: 02637448

Use it or lose it?!

Hmmmm in the hsp world, it's a tad different, as we all know HSP is progressive. This means that the spg will activate any progression that it has in its instructions, regardless of keeping active or forcing oneself to 'walk'.

BUT! It's VERY important to do what you can whilst you can, taking into consideration any progression that is happening at any one time. Using mobility equipment and maybe AFO's to help support you, which in turn can help us walk for longer than without this help.

Physio & exercise will help keep ones muscles that do work, stay as supple and strong as they can, which in turn cuts down on any cramps/spasms and pain associated with it.

That in itself is encouraging to me and helps me start the exercises/physio, although some days it doesn't happen.

That is 'ok' because, apart from the fact that the body is tired/fatigued it's good to rest and other days, maybe one is tired from enjoying life and having a busy day.

The body/limbs say 'no'.

Other days when I do manage my exercises/physio, I feel that I have achieved and feel good about it. But, I also do not beat myself up for not doing any.

Still! We all have 'off' days. That is ok too.

Do what you can, when you can.

Little & often is key.

Do not over do it. I literally can't, as my body/limbs do not comply when it's had enough. Plus, you could make things worse by doing so.

Anyway! That's the end of today's lesson. Lol

Have a GOOD day.

Della Brookman

Charity Fundraising Night

It's an absolute pleasure for me to be able to take some of your newsletter to share with you an event I organised recently to raise funds and awareness for HSP. I know that my father, Ian Bennett, has mentioned that I will be running the London and Edinburgh Marathons in order to raise funds for the HSP charity.

On Saturday 24th March, I organised a charity fundraising night, which included a quiz, a raffle, a charity auction and live music which was held at Cobham sports and social club which is on the outskirts of Wimborne where I live. The club was perfect with it providing the facilities needed for the quiz, band and at least 150 people. My father and fiancé have now

become regulars at this club (they call their visits a requirement, out of a sense of duty).

Arranging this event took a few weeks. One of my friend's parents, designed and printed posters to advertise the night, and tickets. For the raffle and charity auction we went to over 60 companies, both local and international, asking for their support. I was getting very nervous up until the event as I really wanted to make the night a success, and I was concerned that not enough people would turn up, and because I wrote the quiz, I was also worried that it would either be too easy or too hard!

On the night itself, there were approximately 130 people that came, who all paid £5 each for the ticket. Teams were between 4-6 people, and before I started reading out the quiz, I was more nervous than I will be before running the marathons! The quiz was a real success and there were 6 rounds. I was lucky enough to have a local band, One Word, do the music round for me and play introductions of songs instead of me playing them off my phone.

We were very lucky when asking companies to donate prizes for the raffle and the auction. The raffle alone raised £500 with all of the raffle tickets being sold. Prizes included alcohol, chocolates, aftershave, make up etc. The silent auction lots, also mainly came from asking such as an 18 hole 4 ball golf day, cut and blow dry, water park tickets etc, and my company managed to get for me a signed AFC Bournemouth football, which raised over £130 alone. It was brilliant! If anyone is thinking of arranging an event, my advice is to ask as some companies will really surprise you and were very generous in what was donated.

The band One Word performed for over an hour and were fantastic. They performed some of their own music and covers and got everyone dancing. There was also some brilliant wheelchair dancing. The majority of

people at the event did not know the band before the evening but many left wanting to know when and where they could see them again.



Me and the band

After much hard work, anxiety and support from my family, the event was a great success. The total raised from the evening was £1515 and raised further awareness in HSP. I couldn't have done this without the generosity and time from others, especially Cobham Sports and Social Club and the very talented band called One Word. I am truly proud of the event and what I have been able to achieve, as it was so much better than I could have ever dreamed.

Jade Bennett

You wouldn't peel a potato with your bare hands?

It's 2018 and there are so many technical advancements, none of which are essential to life but all designed to make living easier and more enjoyable. We humans have become very adept at making life easier, from stone tools to the electric can opener, through to the invention of the wheel and the car. A huge part of living is adapting one's lifestyle and using what is available to us in order to get the most from life.

I was born with a rare muscle condition which effects my mobility and over the last few years its deteriorated to the point where many of the hobbies and interests have had to be put aside.

Life has been put on hold. I have missed days out at the park with my children, I've missed family days out to the sea side. We as a family haven't been able to explore the local woodland, National Trust or other locations like we used to, because of my own pride.

I love being outside especially with my family but when my family have gone exploring I have sat it out, waited on a bench, in a cafe or back at the car because I just can't do the walking and I don't want to slow them down. I want to play in the park with my children, push my daughter on the swing and teach my son how to climb a tree, but just getting to the tree is painful.

My issue is clearly mobility, there are literally thousands of mobility aids on the market. Why aren't you using one I can hear you scream! Well my stupid pride wouldn't let me. "I'm not having a scooter" "I'm not getting on one of those" was a constant reply every time someone suggested a mobility scooter. Let's be honest, they don't exactly have a good reputation do they? Wrong! So so wrong in fact.

I bit the bullet and quite frankly can tell you that no one cares. In fact, every stare and glance I've had since being a scooter rider has been positive, given with a smile and several comments of "that's cool!" One little boy even asked his dad, "Why can't we get one of those". Then one trip out with my children at the park a little girl came over in her wheelchair and said "I like your scooter, my mommy says when I'm a bit older I can have one too" This one little girl helped me see just how silly I had been.

I soon realised that I had wasted the last 4 years of my life, I hadn't been there for my family in the way I wanted to be. They had missed out on the fun times with their dad. The fun days out are important; it will be

those days they remember. They certainly won't remember the days I sat on a bench and waited for them to return from the park.

It was clear to me that if my pride is holding me back then there are others in exactly the same position, but there was literally nothing available to spur me on or point me in the right direction. So I decided to blog and vlog about my journey with my TGA Maximo. The best thing about living now is there are literally scooters for everyone from full off road scooters that will cross a ploughed field to light and nimble scooters for shopping and drinks around town. I have one in-between a folding scooter with suspension but she fits in my 4x4. It is exactly what I need for my lifestyle and interests. We've developed a bit of a bond too because of the freedom she has given me.



Ross enjoying time at the park with his children

The best thing about being a scooter user is the freedom and spending my time doing the things I love. My longest journey to date is 7 miles. When was the last time you did 7 miles without the car?

I've seen wild deer, played with my kids on many adventure playgrounds and spent over 4 hours touring an RAF Museum to name a few. I'm already planning my spring/summer adventures.

I have started to live life again and after all isn't that what technical advancements are all about?

There is a reason someone invented the potato peeler and why there is one in every kitchen and if you have mobility issues there's a reason you should consider using a mobility scooter. Try it! Go to a National Trust venue, many hire scooters for £5, have a day out and if you don't enjoy yourself feel free to tell me on my blog www.rossminton.co.uk.

Or if you read this and still aren't convinced go to your kitchen now and throw away your potato peeler!

Ross Minton

Angela Norris

It was with sadness that we recently learnt of the death of one of our members from South Wales. Angela Norris from Talbot Green, near Cardiff died on December 18th, aged 69 years.

Angela was diagnosed with HSP at the age of 50 and consequently took early retirement from her position as head teacher of a Nursery school. She lived a full and happy life and refused to allow her HSP restrict her from her pursuits and interests.

Angela sang with several choirs including BBC National Chorus of Wales.

Angela's family have told us that she was grateful for the advice, guidance and support offered by The HSP Support Group and its members that brought comfort and reassurance with the challenges she faced with HSP

In the hope of helping others with HSP, Angela left us a generous donation in her will and funds were also raised through donations at her funeral.

HSP Group Grants

Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier. The maximum grant available is

currently £750. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Regional News

Malton Meeting

We met on 17 Feb at Malton

We had chosen the Old Lodge Hotel which was suggested by a member.

There were six of us, all ambulatory. I doubt though that anyone in a wheelchair would find it accessible as most doors were old-fashioned width. The staff were very good and helpful.

We had really good chats.

One person did stay and found town good but I have not yet heard how he found the hotel.

We are looking for a more accessible place that has its own carpark.

Malton is a good place as it is easy from Leeds and York as well as the Teeside, Humberside and coast plus the surrounding scenery is fantastic - mostly AONBs or National Parks

If any local person can suggest anywhere it would be helpful

Mike Cain

Stockport Meeting 17 March 2018

Despite the snow the meeting went ahead at the meeting room in Stockport, Greater Manchester. Seventeen people made it and 4 sent apologies as they couldn't make it as well as others who thought they might come.

We had a most interesting talk from Neurophysiotherapy.co.uk where I attend for neuro physio. Claire referred to their website where they have stills of

recommended exercises at <http://neurologicalphysiotherapy.co.uk/exercise-library/>. It is useful to look on Youtube where some videos are available. I chose you tube videos physio exercises where it starts with Sciatica. We were also referred to the National Institute of Clinical Excellence (NICE) where pathways are defined and that you are ENTITLED to treatment. The random postcode lottery is shown as they have a contract with Stockport CCG where the waiting time is 5 days. They have connections with clinics in other parts of the Northwest and Leeds. They also accept private referrals. For those of you that live elsewhere, you can google BOBATH therapists but you should always have an assessment before treatment.

We also talked about neurology services for children as we had three under 20s there. The way the NHS services are organised there is a distinction between CHILDREN and ADULT services. There is also a transition service available to those between 16 and 19.

Each area has a fund for treatments they do not routinely fund. Depending on where you live it has a different name but I understand it is called the Individual Funding Request.

Individual funding request appears to be the new name for this funding which is on a single patient basis.

It is often helpful to have a report from a treating physiotherapist to support the application, which may need to be paid for as a private patient initially to create a supportive report.

You make a case and it is considered. (It sounds a similar process to accessing treatments as are often on TV).

I'm afraid it is another bureaucratic chore but you need to ask as often your doctor will not know it is available (we were given a local example where some doctors do not know what is paid for and how we patients can benefit). You can start with NICE

pathway to neurology, MS and looking for similarities.

We talked about most of the points Claire raised and she was most informative. Then she left and we had a long chats over tea and biscuits which people helped to make and wash up. (Thanks to all who helped).

We had a debate whether a purely social or some medical input was best. Socially we can meet in a pub or hotel but we need to have an idea of numbers. If we have other input an accessible place is best. We had both views

Some folk sampled the nearby Beefeater and Premier Inn and the ease of motorway virtually to the door were commented on. Other tastes are catered for locally-Chinese, Indian, McDonalds Pizza etc.

The place had ample room, a car park and vast disabled toilet and it was all easily accessible.

We are meeting in the same place again on Sat 29th September 2018 and Sat 16th March 2019 and people are very welcome.

Irena Pritchard & Mike Cain

Ashburton Meeting

Twenty one members and partners/family members got together at The Dartmoor Lodge Hotel in Ashburton on April 7th.

Heidi Watson, the CEO of the Calvert Trust in Exmoor gave a very interesting presentation on the great work of her organization. The Calvert Trust Exmoor enables people with physical, learning, behavioural and sensory disabilities to experience exciting, challenging and enjoyable outdoor activities. We were shown slides and a video of the amazing activities on offer and some of our members are definitely tempted to get involved. Further information on the Calvert Trust Exmoor can be found at:

<http://www.calvert-trust.org.uk/exmoor/exmoor>

During our afternoon together, we had our usual raffle which raised £70 which more than covered the cost of our teas and coffees. I naughtily forgot to thank Lorraine Saupe for her help with the raffle so I'll take the opportunity to do that now. THANKS LORRAINE!!!!

Members had the time to chat to one another and I congratulated Tracey Aggett for being successful in her application for a flying scholarship from the charity FSDP.

Twelve members stayed overnight in the hotel so we were able to have a very enjoyable dinner together (the lamb shank was delicious), before gathering in the bar to enjoy a drink or three.

We all met for a lovely full English breakfast on Sunday morning before making our way home.

As always the staff at the Dartmoor Lodge Hotel looked after us very well and we have booked our next meeting to take place on October 13th.

Ian Bennett

Colchester Branch Meeting

Our meeting at Feering, between Colchester and Chelmsford, was very nearly hijacked by the wintry weather which reached us from Siberia. However, we held our nerve and, in the end, conditions were reasonable around Feering and only three people were unable to come because of snow at home.

John Patching had arranged for his neurophysiotherapist, Sasha, to join us to talk about HSP and physiotherapy. She had come some distance from her home to be with us, gave an excellent talk with demonstrations of the types of exercises which can be helpful in HSP, answered our many questions throughout and was happy to discuss issues in more detail with individual members both before and after her talk. Nearly all of the twenty or so members present joined in the discussions

and, I hope, found the afternoon helpful. I certainly did.

Sasha covered both stretching and strengthening exercises and talked of the advantages of general activity which, for some might be pottering and not sitting for too long while for others might be requesting a GP referral to a local gym. She told us that it is possible to buy "pedometers" for wheelchairs which count the number of revolutions.

She talked of the value of standing if possible, perhaps at the kitchen work surface, saying that this can give a good stretch as well as being generally beneficial for anyone who has to spend quite a bit of time sitting down.

On the question of balance issues she stressed that flexible ankles are very important for balance so keeping the ankles moving as far as possible is helpful. For those who experience reduced sensation in the feet she explained that this can cause balance problems.

Sasha also explained Functional Electrical Stimulation saying that it can be very effective indeed though it can be difficult to obtain funding.

She encouraged anyone who does not, currently, receive neurophysiotherapy support to request a referral.

Hugh Beavan kindly thanked Sasha on our behalf for a very worthwhile and enjoyable afternoon.

We missed those who weren't able to come this time but were very happy to welcome two people who had not been to one of our meetings before.

We shall be meeting again on Sunday, 14th October from **2.30** – 5 pm at Feering Community Centre, near Colchester, Essex, CO5 9QB. As always, everyone is very welcome to join us.

Hilary Croydon

Forthcoming Events

HSP Support Group AGM

Saturday 9th June 10am – 4.30pm
Tally Ho Conference Centre
Perschore Road
Birmingham
B5 7RN

Birmingham Meeting

Saturday 21st April, from 12 - 3pm
The Kenrick Centre
Mill Farm Road
Harborne
Birmingham
B17 0QX
Contact Penny Cohen: 07818 288 738
Email: pennycohen57@hotmail.com

Ashburton Gathering

Saturday October 13th 2pm onwards
The Dartmoor Lodge Hotel
Peartree Cross
Ashburton
Newton Abbot
TQ13 7JW
Call Ian Bennett on: 01202 849 391

Milford Afternoon Tea

South/South East

Sunday November 11th 3pm – 6pm
The Clockhouse
Milford
GU8 5EZ
Call Jane Bennett on: 020 8853 4089

Colchester Meeting

Sunday, October 14th 2.30 - 5pm
Feering Community Centre
Feering
Essex
CO5 9QB
Call Hilary Croydon: 01284 728 242
tohiti@btinternet.com

Stockport Meeting

Quaker Meeting House
2 Cooper Street
Stockport
SK1 3DW
(For sat Nav use: SK1 3QL)
Saturday 29th September 2pm – 5pm
Call Irena Pritchard: 01524 261 076 or
Mike Cain: 01614 567 531
irena.pritchard@btinternet.com

Region 3 Social Meeting

Saturday May 19th 1.30pm - 4pm
The Orange Tree Public House
100 Stevenage Rd
Hitchin
SG4 9DR
Contact Della Brookman: 07710 637 941

Potato Pants Music Festival

Friday 1st June 2018 from 7pm - 11pm
Saturday 2nd June 2018 from 2pm - 11pm
High Mead Farm, Ham Lane, Ferndown,
Dorset, BH22 9DR
Request disabled parking (much closer)

New Members

We welcome the following new members:

Jacob Powell
South Wales

Neil Blencowe
West Bromwich

Ray Martyn
Nottingham

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

Useful Contacts

	Email	Telephone No:
Adam Lawrence - Chairman 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	adam@idios.co.uk	07834 505 161
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	dave@vadcar.org.uk	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
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Barbara Jones – Norwich co-ordinator	babs27833@gmail.com	01603 423 267
Liz Redmond - Neurogenetics Nurse based at The National Hospital of Neurology & Neurosurgery	Redmond.liz@uclh.nhs.uk	02034 484 487